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**Judging Quality: Parents'
perspectives of the quality of their
child's hospital care**

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**Doctor of Philosophy
University of Northumbria at
Newcastle**

2017

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perspectives of the quality of their
child's hospital care**

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Abstract

Background

UK healthcare has adopted various improvement strategies from business including using satisfaction surveys. However, the way patients form and express judgements of quality care can be more complex than customer purchases. Research in adult patient satisfaction has found capturing patient opinion challenging; however, adult service-user views continue to underpin quality care guidance across healthcare. Development of knowledge to include parental views of quality care is important to inform future guidance specific to children's services.

Methods

This study aimed to examine how parents determined the quality of care provided when their child was hospitalised, factors influencing perceptions of care and whether these judgements changed over time. Using a grounded theory approach, data were collected through a series of in-depth interviews (22) with nine parents following their child's hospitalisation.

Findings

The substantive grounded theory - ***Parenting in an alien hospital world: on guard and on behalf*** offers new perspectives on the complex psychosocial processes underlying parents' quality judgements. When their child was hospitalised parents landed in an 'alien' world but continued to try 'to parent' (protect and advocate) their child. Parents' experiences were characterised by landing; moving from being 'new parents' to 'old hands'; searching for and judging the 'clues' and facing dilemmas of how best to respond to professionals. Parents were found to use an escalating level of signals to prompt health professionals to respond to their queries and concerns. Parents' personal lens altered through their transitional journey and this, together with their perception of professionals' power impacted on their chosen responses to professionals and their quality judgements. Parents held two views of care quality: 'at the time' and a final 'on balance' view. The final view recognised their own heightened emotions and reflected their current transition.

Conclusions

Ultimately parents judge hospital care as high quality when they perceived health professionals acted as their allies in their parenting roles as protectors and advocates for their child in the alien hospital world. Health professionals could improve parents' experiences and quality judgements of care by early recognition and response to their 'signalling' and by explicitly acting as parental allies.

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Declaration

I declare that the work contained in this thesis has not been submitted for any other award and that it is all my own work. I confirm that this work fully acknowledges opinions, ideas and contributions from the work of others.

All the required ethical clearances for the research presented in this thesis have been granted. Approval and research access has been sought and granted by the Local Research Ethics Committee, Northumbria University School of Health, Community and Education Studies Ethics Committee (now known as Faculty of Health and Life Sciences Ethics Committee) and the Research and Development Department of the Trust included in this study.

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Chapter 1

Introduction

In this first chapter the aim is to set out the purpose and direction of the study and to share my personal background and motivation for choice of research topic. The context for the study is then provided before the chapter concludes with an outline of the structure of the thesis. The following sub-headings form the framework of this chapter: my personal story and study's origins; background and context; children's hospital care; judgement; changing position of patients; customers; patients as consumers; dissatisfaction and complaining; changing nature of the patient population and concludes with an outline of the structure of the thesis.

This grounded theory study was undertaken to appreciate parental perspectives of the quality of their child's hospital care and to explore how parents judge quality of care. Development of this knowledge base is important to inform future quality improvements in children's hospital care provision. Health service policies and guidance relating to quality improvements in hospital care have often been based on literature dominated by adult patient perspectives (Department of Health (DOH), 2007a; Department of Health 2007b; National Nursing Research Unit (NNRU), 2008). Key themes identified as important aspects of care from adult patient perspectives are, getting the basics right; fitting in with my life; treating me as a person and working with me as a partner in my health (DOH, 2007a). All health care professionals have been urged to specifically address these issues for all patients in all settings (NNRU, 2008)

although this message fails to recognise potential differences between child, parent and adult patient perspectives on quality care.

In recent years, UK health care has seen the adoption of various service improvement strategies from the business world; these have included satisfaction surveys and an emphasis on service user feedback. However, the way that patients form and express their judgements of hospital care can be more complex than a customer buying a product or service. Accessing the real views of patients can be challenging (Williams, 1994; McIver and Meredith, 1998) and in adult patients, transformation of opinion over time from initial negative to more positive views of quality of care has been noted (Edwards 2003; Edwards et al, 2004). It is not known whether this transformation of opinion also occurs when parents judge the quality of their child's care, nor do we know if the key aspects of care valued by adult patients also matter to parents of hospitalised children. It is essential, therefore, that research is undertaken specific to children's hospital care to expand the evidence base about how judgements of quality care are made by service users rather than assuming that their perspectives will be the same as adult patient perspectives.

The service user in children's health care is a title that can be applied to children, young people, parents/carers or family and all perspectives are significant and important. The focus selected in this study was the parents' perspectives, on the basis that they occupy a unique position as both an observer and recipient of care in services which aim to provide family centred care. Parents' perspective on the quality of their child's hospital care is important as they are responsible for their child's well-being inside and outside of the hospital and before and after the experience. In addition, they are central figures in their child's life; have responsibilities and rights because of their

position as a parent; access health care on their child's behalf and may be a key provider of their child's future care needs. It is for these reasons that this study explored the parents' perspectives on judging the quality of their child's care.

My personal story and origins of study

I began nursing over thirty years ago registering initially as an adult nurse before moving on to become a registered sick children's nurse. The majority of my clinical work focused on acute care of children and families in hospital. My career has provided opportunities to gain experience in clinical practice, nursing management, practice development, education and research. During that time my motivation has remained the same: to improve the quality of care for children and their families. Throughout my career it is this personal motivation that has led me to seek out various senior positions in children's nursing to enable me to contribute to this important agenda.

Whilst quality has always been in the forefront of my mind as a nurse, the seeds for the focus of this study - the parental perspective of quality - were sown many years ago when a critical incident occurred. Working as a nurse manager in an acute children's unit, a letter of complaint was received from a parent about the care of his child on one of the wards. It was a little surprising to receive a complaint, partly because it was the 1980s and it was rare for parents to send letters of complaint to the hospital and also because, in my opinion, this was a "good ward", where the quality of care for children and their families was of a high standard. Reflecting on the starting point for this study made me

realise how significant this experience was and how it not only influenced the choice of topic for this research but has also been used many times in teaching children's nursing students.

After reading the letter the reasons that this parent had written formally about his complaints were understandable. Sarah was 13 years of age and had been involved in a road traffic accident sustaining a fractured femur. A Thomas splint was used to immobilise the fracture, meaning Sarah was confined to bed for approximately eight weeks. The father worked away from home and described how his wife had visited the hospital each day but could not be resident because they had two younger children at home. His wife took the two younger children to school and nursery before getting two buses to the hospital before visiting Sarah: this journey lasted over an hour. No matter what time Sarah's mum arrived on the ward, Sarah would be waiting for her to undertake the daily bed bath. Her mum often found that Sarah had also waited until she arrived to use a bed pan. During the hours she spent on the ward, Sarah's mum undertook all of her care before heading off for her buses, worrying in case she would be late to pick up her other children. After many weeks Sarah's mum was exhausted and her husband felt that he had to write a letter of complaint. He was shocked that the nurses were not caring for his daughter and questioned why his wife - who was not a nurse - was having to bed bath Sarah, give her bedpans, give her medicines and her meals. He wondered if this was because there were insufficient nurses on the ward.

Unlike Sarah's dad, I was not shocked by the aspects of care that Sarah's mum was involved in, as this was recognisable as parental participation in care which was key to the unit's philosophy of care. However, I was shocked that the parents' perspective of their experience of this approach to care had been so far

from the intentions of the philosophy. It seemed there had been a lack of negotiation and communication between the staff, parents and Sarah and little recognition, if any, by staff of how the mum was feeling about this situation. On talking to the nurses, their perspective was that Sarah was quite shy and preferred her mum to wash her so they always left her for her mum to bed bath when she arrived each day. This message had been passed on shift to shift and had become custom and practice - no one questioned it. The nurses had assumed she was happy with this arrangement as she had not said anything to them.

This complaint was an important moment in appreciating how the same events can be interpreted so differently by those involved depending on their perspective. It was also evident that these viewpoints can cause so many difficulties if there is no effective communication between the parties involved. This incident influenced my approach to clinical practice and it has continued to influence me as my career later moved into teaching and research.

My real interest and understanding of health care research came when I was leading an initiative to introduce the use of calico dolls as an intervention in preparation of children for painful or distressing procedures. This led me to take a part time research secondment during which I undertook a Masters programme in health services research and completed a quantitative study about the use of calico dolls (English, 1999). These experiences helped me to appreciate the relatively limited research evidence base in children's nursing and the need for expansion in this field to enable clinical staff to access research relevant to their patient group rather than relying on evidence from adult care to inform future developments (English and Bond, 1998).

Another aspect of children's care that I felt passionate about was children's rights and together with colleagues in clinical practice and education we embarked on several projects to highlight and improve the application of children's rights within our clinical service. A project entitled Kids Count addressed Article 12 of the United Nations Convention of the Rights of the Child (United Nations General Assembly, 1989) which in simplistic terms requires organisations to listen and act upon the views of children and young people (Cunliffe and English, 1998). Since this time there has been much interest and progress in this area to the point where it is common place nowadays for children and young people to have involvement in service developments. Since this time there has been much innovative work by children's nurses, researchers, clinicians and educationalists (Kirby, 1999; Bradding and Horstman, 1999; Alderson and Montgomery, 1996; Coad and Percy-Smith, 2007; Coad and Houston, 2007; Fallon, Smith, Morgan et al, 2008) that has contributed to development in this aspect of practice. For me, these experiences of listening to children and young people's views taught me about the unseen and unheard elements of their care experiences and the importance of their feedback to service improvement. Again this work shaped my thinking to some extent and therefore further influenced development of this study's focus. Initial ideas for this study were to research quality from a perspective other than the professional one which is usually prominent in existing policies and guidance. Despite my earlier work in accessing children's views and continued interest in this area, the chosen focus was parents' perspective of quality, in recognition of the unique and major role parents play when their child is hospitalised.

Background and context

The next step in setting the scene for this study is to define and discuss key concepts relevant to this research: quality care and its importance for the child and family. Throughout this chapter reference to quality in the context of retail and business will be made to underline similarities and differences that may exist between customers and health care service users. Quality is subjective, individual and contextual in nature making its definition difficult. The Oxford English dictionary offers a definition of quality as:-

the standard of something as measured against other things of a similar kind; the degree of excellence of something

(<http://www.oxforddictionaries.com/definition/English/quality> last accessed 18.6.16).

This definition indicates the conditional, perceptual and subjective nature of the concept of quality and highlights problems associated in individual's determining quality in situations where measurement is difficult; knowledge of standards of similar products or services by the individual is limited and perceptions of excellence may vary. Clearly these problems may be more applicable to health service users than retail customers. If quality is initially considered within retail and business contexts it is evident that the pursuit of quality over the years has been driven by financial rewards for meeting customer needs, expectations and preferences (East et al, 2008). The American Society for Quality (ASQ) indicate that quality is individually determined but interestingly also identify quality as products and services free from deficiency (ASQ, www.asq.org last accessed 18.6.16) which provides another dimension of quality. International management standards - the ISO 9000 standard refers to quality as the extent

to which particular characteristics meet needs or expectations (International Organisation for Standardisation (ISO), 2016) suggesting consumers are best placed to determine if quality has been achieved. This notion of consumer quality evaluation has also been emphasised by Drucker (2015, p.280) a business leader and writer who commented that:-

'Quality' in a product or service is not what the supplier puts in. It is what the customer gets out and is willing to pay for. (p. 280)

Whilst these definitions demonstrate the varied and subjective nature of the term quality they also remind us that judgements of quality are dependent on individual perspectives and reflect their knowledge about what products or services are needed, wanted and available. Novice health service users may be much more dependent on professionals than consumers within the retail world, in this respect, as their knowledge is likely to be more limited.

Care is a term that is universally recognised and commonly used but like quality is complex to clearly define. It can be used as a noun, verb or adjective and its meaning is altered when attached to other words or through context of its use. Similar to quality it has a positive connotation unless prefixed with other words, for example, 'poor' or 'disappointing'. Stockdale and Warelow (2000) note that 'care' has only appeared in nursing dictionaries in the last twenty years where this has mainly been in conjunction with another word, for example, wound care, surgical care, nursing care, medical care or pre-operative care. Health England uses the term 'care' within its public messages, in documentation and on websites, without definition but its implicit meaning appears to be an inclusive term for all services provided to meet patients' health care needs. This

reflects the way that the term is generally used in health care when the aim is not to distinguish between different elements of service provision, for example, medical and nursing care. Using the word in this holistic and overarching way fits with its dictionary definition:-

the provision of what is necessary for the health, welfare, maintenance and protection of someone or something (www.oxforddictionaries.com - last accessed 10/11/15)

In this study the term *care* is used to encompass all aspects of care provided to children and families recognising that their whole experience of care is not necessarily segregated in their minds dependent on who delivered that aspect of care or where it was delivered.

In considering 'quality care' in health services, again difficulties arise in providing a simple definition. The phrase is seen as being a complex concept consisting of many dimensions and factors (Currie et al, 2005): a construct that involves the individual values, beliefs and attitudes of those receiving and providing care (Gunther and Alligood, 2002). Notions of what may constitute quality health care has altered over the years reflecting changing values within society. An emphasis on continual quality improvement and increased patient and public involvement in health services began in the late 1990s (DOH 1996b; 1997; 2000a; 2001a; Health and Social Care Act, 2001; Picker, 2002) and NHS quality improvements were later championed by Lord Darzi who specified that quality should include; patient safety, patient experience and effectiveness of care (Lord Darzi, 2008). He believed that improvement in health care experiences was dependent on professionals analysing and fully understanding

satisfaction with care through the service user's own experiences. Changes in services to increasingly incorporate patient satisfaction or feedback mechanisms were adopted and continue to be a requirement within service provision. The philosophies of care underpinning adult nursing and children's nursing care differ somewhat with adult nursing focussing on person centredness (McCormack, 2004; Innes, MacPherson and McCabe, 2006; McCormack, Manley and Walsh, 2008; RCN, 2009a; McCormack and McCance, 2010; Kitson et al, 2013) and children's nursing centring on family centred care (Smith et al, 2002; Baker, 1995; Bridgeman, 1999) and parental partnership in care (Casey, 1995; Coyne, 1995a; Coyne, 1995b; Callery and Smith, 1991). The philosophies of adult and children's care, whilst different in focus, are both recognised as being central to the provision of quality care within their individual fields of practice.

Children's hospital care

The family centred care philosophy within children's healthcare has not always been in place. In fact, it is in sharp contrast to traditional approaches of care existing in the 1950s where children were separated from parents in the belief that this was best for them and that parental visits further distressed children (Nethercott, 1993). It was recognition of acute emotional distress and potential long term adverse psychological effects later in life (Bowlby, 1971; Bowlby, 1973) that prompted an enquiry into the welfare of children in hospital in the UK. The findings were subsequently published in the Platt Report (Ministry of Health, 1959) which recognised the emotional needs of hospitalised children and recommended unrestricted visiting, resources for play, opportunities for

mothers to stay overnight with their child and staff education to include the psycho-social needs of hospitalised children. This report is credited with changing the face of children's hospital care. However, progress was slow as care approaches moved from those of the 1950s to the present day where the current philosophy of care aims to fully involve parents in all elements of care.

Family centred care is recognised as being key to quality care provision for children and families as it enables parental participation and mitigates against potential adverse effects of children's hospital experiences (Jolley and Shields, 2009). Children's nurses have a duty of care to deliver high quality and safe care to children and families (NMC, 2015) and it is vital that the progress made on improving the quality of children's hospital care continues to be developed and strengthened. Children's early experiences of health care can impact on their attitudes, behaviours and access to health services in their adult lives and it is, therefore, essential that children and families have positive high quality experiences. Following the Bristol Inquiry, Sir Ian Kennedy (Kennedy, 2001) urged health care professionals to ensure quality care experiences for children and families as well as positive clinical outcomes, clearly recognising the major impact on families of poor quality experiences of care.

Despite its universal acceptance as the philosophy guiding practice in this field of care (Coyne 1995b; Kawik 1996; Hutchfield 1999; Newton 2000; Franck and Callery, 2004; Corlett and Twycross, 2006), its implementation in practice has not always been straightforward. Debates in the literature over many years have identified a number of problems with the reality of this philosophy in practice (Callery and Smith, 1991; Darbyshire, 1994; Dearmun 1992; Coyne

1995b; Hallström et al 2002; Coyne et al, 2011). Lack of information, communication and appropriate negotiation between nurses and parents have been identified as barriers to effective partnership working (Callery and Smith 1991; Dearmun, 1992; Kawik, 1996; Neill 1996; Hallström et al, 2002). A number of authors have identified power and control issues as underlying the difficulties parents face in negotiating care with nurses (Neill 1996; Darbyshire, 1994; Kirk, 2001) and recognise that the nurse is the gate-keeper to participation through their position and power (Smith, 2002; Tomlinson et al 2002; Corlett and Twycross, 2006; and Coleman et al 2003). In addition, it has been argued that there is no rigorous evidence to demonstrate the effectiveness of family-centred care (Shields, 2010). However, this matter has not in any way deterred its recognition as being central to quality health care for children within Government policy (DOH, 2003); by professional bodies and by children's nurses themselves (Coyne et al, 2011).

Judgement

It is important now to consider the concept of judgement, given a key aspect of this study relates to parental judgements of quality of their child's care. Judgement has been described as making an assessment between different alternatives (Dowie, 1993) which gives a sense of the requirement of the "judge" to both appraise and decide. The process of judgement is further explained by Maule (2001) as appraisal of a range of pieces of data to provide an over-arching assessment of individuals, objects or events. Whilst these definitions of the term judgement are helpful they do not address factors that may influence judgement formation or the potential subjectivity of many judgements. In addressing these issues, Cooksey (1996) argues that there are

three factors influencing an individual's ability to make a correct judgement:- predictability of the world; knowledge base of the individual in relation to the world and how consistently individuals are able to apply their knowledge. Clearly in some situations where judgement is used there will be a means to determine whether the person's judgement at the time was correct, for example, where a train driver judges the track up ahead to be unsafe and decides to stop the train before he reaches that point. In other circumstances there may be no correct judgement as it may merely reflect a personal perspective on the situation they are judging that is required. In these situations the judge may still appraise information to help them to draw a conclusion and produce a judgement but this will not result in a decision or an action but the determining of their viewpoint on the situation.

In judging the quality of a health care experience there may be additional factors that may influence an individual's judgement for example, Staniszevska and Henderson (2005) found that adult patients' evaluations of care was influenced by a range of factors including gratitude, loyalty and luck. In addition, Fitzpatrick (1993) suggests that some form of normative effect may also operate to inhibit criticism in people's judgements of health care experiences. Taking account of these different perspectives on judgement it would seem that any judgement of quality of care by patients will provide their own perspective of the situation but this may be influenced by a range of other factors as seen in Staniszevska and Henderson's research with adult patients (2005).

Power and control held by health professionals within hospital environments is well recognised and has been discussed earlier in this chapter in respect of

NHS modernisation (Bissell et al, 2004; Greenhalgh, 2009). The use of professional authority by doctors and nurses to exert their control within health care has been evident historically and mirrors Foucault's reference to a regime based in truth (Foucault 1980) whereby those with exclusive specialist skills and knowledge prevail. In children's hospital care these power issues have been equally well recognised in relation to partnership working with parents, a central aspect of the philosophy of family-centred care (Neill, 1996; Darbyshire, 1994; Coyne, 1995a; Coyne, 1995b; Newton, 2000; Kirk, 2001). It would seem likely that the perceived power of professionals within health services could impact on how service users make judgements of care and their ability to provide honest feedback on their experiences in a way that is quite different to customers buying products or services. The context in which parents experience and evaluate their child's hospital care has changed considerably in the last few decades and this needs to be considered at the outset of this study. The position of parents in relation to health professionals and the National Health Service (NHS) has also altered over the years and it is important to recognise that these changes form the backdrop to parental judgements of the quality of their child's hospital care.

Changing position of patients

The historical background to these changes will be considered here to appreciate their potential impact on current care and parents' evaluations of quality of care provision. In the 1980s, the government attempted to introduce competition into health services by developing a "purchaser" "provider" split in services. At that time there was much talk of patients as "customers" and the

NHS as a business. There was also discussion about creating a marketplace in health care in which quality of services would be improved through competition, in the way that businesses operated in the open market with only the best surviving. Money was to “follow patients” and it was acknowledged it would be a case of the survival of the fittest organisations. Whilst ultimately this situation was altered to some extent when the next government came to power the seeds had been planted for a shift in the perception of the health service by the public. In some ways this was the beginning of a philosophical shift from being a passive patient within the NHS to becoming a health care consumer. At the same time as these changes in health care were taking place society was also seeing similar changes in other walks of life as the age of the Charter rolled in (DOH, 1991a). The notion of active citizen consumers was born in this era and as key public policies continued to encourage this concept, changes in the public's mindset was perhaps inevitable (Laing et al, 2010). In this new world the British public with their reputation for being quite reticent about complaining were, in essence, being given permission to complain as charters abounded detailing the standards and services the public had a right to expect or indeed to demand.

Government plans to modernise the NHS during this era were outlined in a range of documents and policies (Department of Health 1996b;1997; 2000a; 2001a; Health and Social Care Act, 2001). This re-design of the service incorporated a number of elements aimed at strengthening the position of the patient e.g. greater patient and public involvement, development of a Patient Advisory Liaison Service and launch of the National NHS Patient Experience Survey (DOH, 2000a; DOH, 2002a; Picker, 2002). These new initiatives were

seen as addressing some of the perceived imbalance of power between patients and health professionals. Availability of information for consumers became a familiar theme in public policy including health policy. At the same time, technological advancements enabled the public to have quick, easy access to a huge range of information that was previously the preserve of the professionals (Laing et al 2010). Information has long been recognised as central to empowerment of individuals (Foucault, 1980). It is not surprising then that the impact of public and health policies alongside unprecedented access to information through the internet resulted in shifts in the roles and power relationships between patients and health professionals (Laing et al 2010). Messages within subsequent health care policy continued in this vein with demands to increase patient choice, information provision, encouragement of individual responsibility for personal health as well as active patient involvement in decision making (DH 2006a; DH 2006b; DH 2004a; DH 2004b).

Empowerment of the public and patients within the NHS has continued to grow with more recent changes allowing individual patient choice of hospital for planned admissions. Further changes to funding through PbR (payment by results) re-introduced a competitive element to service provision (Audit Commission, 2004) which then provided a further imperative for health care providers to better understand the factors influencing patient's views on service provision. Patients' and the public views of health services have been seen as much more important in recent times and consultations with them have become an expectation or even a requirement in developing and monitoring services. The idea of consumer feedback is a familiar concept within service industry and business but this has been something new for the NHS to come to terms with where historically, the professionals 'always knew best'.

The idea of patients being seen as a "consumer" in health care emerged during these changes in society, public and health policy. Increasingly patients were referred to as customers or service users in policy documents and health care was likened to the service industry and business. It was envisaged that viewing patients as consumers and health services as service providers would bring quality service improvements to health care that had been witnessed in retail and business. In that world, of course, customers held more power in the relationship than patients did within the NHS. Whether such comparisons are justified is debateable and will be considered later in this thesis as the concepts of accessing NHS users' views, patient satisfaction, judgement of quality of care and the parents of hospitalised children are all considered.

Interestingly in the competitive business world the quest to understand customer satisfaction and expectations of products and services occurred well before such strategies were even considered as important in the NHS. Marketing executives quickly recognised that customer satisfaction and expectations were linked to buying behaviours and therefore this became a focus of attention to increase profits and success.

Customers

Matching consumer expectation with service provision or goods was initially seen as defining 'consumer satisfaction'. Oliver (1989) noted that there was often a level of contentment in the consumer which was linked with a fairly low level of expectation e.g. a consumer being satisfied with purchasing a fridge if it maintained food at a cold temperature. This was seen as the 'confirmation

model' which was characterised by a low arousal state in consumers whereby their low expectations were met or confirmed. Customers discontent was also recognised in situations where they had negative expectations which were actually met by the goods or services purchased. It was then also apparent that people could equally become used to inadequate services or goods and this led to a situation where they were subdued in displaying discontent and this reaction became habitual. In this scenario consumers are found to rarely feedback their content or discontent unless questioned or if the shortcomings of the service or goods are pointed out to them. Over the years, advertisers have used this knowledge in their campaigns by pointing out the shortcomings of their competitor's products to raise customer's awareness.

The seminal work of Helson (1964) in this field, identified that the public's willingness to tolerate problems with goods and services could be explained by Adaptation Theory which acknowledges that perception is related to a benchmark which may alter over time, dependent on individuals' experiences. It was believed that small deviations from expectations would ultimately have little impact on the benchmark. If consumers have little awareness of shortcomings of everyday products, they will feel little pressure to take any action to try to fix these problems and our tendency to just adjust to the situation further perpetuates this state of affairs. When poor products or services are frequently experienced, it means that habituation can lead to absence of any complaint or an effort to find or change the product or service.

Many of the discontents that we experience in public services tend to be longstanding problems so it is possible that we become accustomed to them and almost anticipate some negative experiences. For example, many patients may anticipate and tolerate a lengthy wait at a hospital out-patient appointment

before being seen, despite being on time for the appointment themselves. In health care, limited alternative services for patients to access may influence their acceptance of such negative experiences. Whereas in business/retail, customers can usually take their custom elsewhere, patients are not usually in this position. In addition, the notion that complaining about problems within health services may be a difficult process may also deter potential complainants. Research has moved on from the confirmation model within retail but we can see that this explanation of consumer satisfaction may explain the way we behave as customers in many settings or, for example, in the patients' tolerance of waiting times in the NHS.

A further customer satisfaction model is the disconfirmation model (Helson, 1964) this is where a consumer is positively or negatively surprised by product features or service quality. In this model the magnitude of surprise is related to the size of discrepancy between expectation and experience. Large deviations from customer's expectations will affect perception and change adaptation level. Retailers and service providers in search of quality improvement began focusing efforts on understanding and responding to these situations, i.e. where goods/services disconfirmed expectations, either positively and giving satisfaction or negatively and causing dissatisfaction.

Further developments in quality improvements through ensuring customer satisfaction focussed upon 'service encounter'. The 'service encounter' is where customers come into direct contact with service providers and this is seen as a key interaction with these encounters being referred to as 'moments of truth' (Carlzon 1987; Dale 2003; Edvardsson and Nilsson-Wittell 2004; Normann 1984). Dale (2003) re-iterates that each 'moment of truth' influences service users' overall opinion and evaluation of any service and notes that it is

the customer who ultimately judges whether services are of high quality or not. This may apply in business and retail but may not necessarily fit within healthcare where service users may have less knowledge of what constitutes high quality service provision in terms of clinical and technical terms. Despite this healthcare service users will, of course, have a view of how they perceive the quality of their experiences and this cannot be disputed as this is their personal perspective.

There is a limited and relatively dated body of research in the field of business marketing which has examined customer satisfaction and has mainly tried to discover the issues that are classed as 'satisfiers', 'dissatisfiers', or both (East et al 2008). An American research study which examined restaurant complaints and compliments (Cadotte and Turgeon, 1988) identified the factors that were seen as satisfiers, dissatisfiers, criticals and neutrals. These terms were defined as:-

- a dissatisfier - an element, the lack of which causes dissatisfaction but the presence of which does not cause satisfaction
- a satisfier - an element that if present leads to satisfaction but if absent does not cause dissatisfaction
- criticals - elements which are both satisfiers and dissatisfiers i.e. presence leads to satisfaction and absence leads to dissatisfaction
- neutrals - presence does not cause satisfaction nor does absence cause dissatisfaction

Similarly, Johnston (1995) identified that whilst some determinants of service quality may be viewed as important to consumers their absence does not

necessarily lead to dissatisfaction. Parasuraman et al (1985) developed the key elements of service quality which were meant to be transferrable to any organisation - ServQual. The original work contained 22 items to determine service quality which fitted within five key domains. Original claims that this model could be applied in a universal way to services were later contested. Johnston (1995), and also Cadotte and Turgeon (1988), proposed that such determinants were not particularly mirror images of each other and correcting all the 'dissatisfiers' would not necessarily produce satisfied customers.

Similarities are striking between these pieces of work and the much earlier seminal study of Herzberg (1959) on satisfaction at work. Determinants of satisfaction at work were identified as "motivators" in this study. Other factors were named as "hygiene factors" and were found to lead to a lack of dissatisfaction. This was an interesting but quite contradictory notion that motivating factors created satisfaction but hygiene factors merely prevented dissatisfaction.

Patients as consumers

It is evident from previous discussions that the retail and business world became increasingly aware of the importance of listening to customer's views of quality and recognised this was crucial to successful business. Health services have been encouraged to embrace this concept in the last two decades. Various strategies have been employed by successive governments to improve the NHS and align more closely service provision with public expectations, for example, targets relating to waiting times, referral to appointment times and accident emergency "trolley" waiting times. The journey that businesses have made to develop into high quality and successful businesses has almost been

mirrored by the NHS as it has moved through different models of customer satisfaction. This began with the use of customer (patient) complaints or absence of them as a measure of quality and then focus shifted to the development of blueprints and quality standards, for example, NSFs (National Service Frameworks) (DOH, 2004b) for services to replicate and comply with in practice. Active seeking out of customer (patient) service experiences or patient involvement in creating improvements in services is now expected. In recent years, few DOH guidance documents have been published without reference to service user involvement. All areas of health care from delivery of services to education of health care staff have been required to demonstrate some utilisation of service user views or involvement.

Similarly in health service research there has been a recognition and encouragement to engage service users in the processes and to recognise the value of such involvement. An organisation entitled "INVOLVE" was set up in 1996 as part of the National Institute of Health Research (Involve, 2015). This group acts as a national advisory group supporting the public and professionals to achieve involvement within research studies in the NHS, public health and social care. Since they were set up they have shared resources via their website (www.involve.org.uk) and promoted the development of expertise in this area across all age groups. This is a unique group which is government funded, demonstrating the commitment and value that has been placed in recent years on the public involvement agenda within health care. INVOLVE's terms of reference reflect the Department of Health's interest and support for growth in this area for future health and social care. INVOLVE see their role as bringing together expertise, insight and experience in the field of public involvement in

research, with the aim of advancing it as an essential part of the process by which research is identified, prioritised, designed, conducted and disseminated.

This emphasis on service user involvement in health care has also been taken up in children and young people's research. There is growing evidence of children and young people becoming involved in research, despite some of the barriers to this created through their recognition as a vulnerable group and some of the challenges this can create (Clinical Research Network Children, 2016; Bird et al, 2013; Shaw et al, 2011; Sharpe, 2009; Pryse, 2009; Coad and Evans, 2007; Clark and Moss, 2001). There are a number of organisations that have been leading the way in this area and have produced information and resources (Clinical Research Network Children, 2016; National Children's Bureau Research Centre (NCB), 2016) and a number of publications exist which demonstrate involvement strategies (Sharpe, 2009; Pryse, 2009; Coad and Evans, 2007) and provide guidance on involving children and young people in future research studies. INVOLVE has also published guidance on involvement of children and young people in research (Kirby, 2004). In addition, to young service users being involved in research there have been advances in their involvement in service developments and health professional education development.

A good example of how young health care consumers have been fully involved in the setting of standards and evaluating services has been through the "You're Welcome" accreditation (DH, 2007b). This scheme was introduced by the Department of Health to improve health care services in ways that would appeal to young people and encourage their future utilisation of the services (DH, 2007b). This scheme has proved popular with staff and young people resulting in effective engagement in the service improvement process and accreditation

for many services who achieve the quality criteria of the scheme (Hargreaves, 2011; Hargreaves and Viner, 2012). Young people have been involved as assessors within the scheme as well as acting as 'mystery shoppers' in some settings. This initiative draws on some of the methods used in service industry to ensure first impressions of a service are positive. In addition, the scheme identifies key standards that need to be met for a service to gain accreditation in the same way that star ratings for restaurant or hotel services are awarded. There has also been discussion in the literature (Simons, Tee and Lathlean et al 2007) and practical examples of service user inclusion in development of education programmes in health care (Davis and McIntosh, 2005) including young patient involvement in designing post-registration modules within adolescent care (Fallon, Smith, Morgan et al , 2008).

It is clear having considered the background and development in service user involvement over the years that the importance of patient and parent/carer experiences of and satisfaction with care is now viewed as an essential feature of today's NHS. In the adult field of health care there is some evidence which has examined adult patients' experiences and patient satisfaction (Carr-Hill 1992, Fitzpatrick 1993, Williams 1994, Edwards and Staniszweska 2000, Aspinall et al 2003, Edwards et al, 2004). This work supported the Department of Health's campaign to raise the quality of care provided to patients (DOH 2007a). Despite various attempts to further explore patient satisfaction in the adult population it has been acknowledged that progress has been thwarted through a lack of conceptual and theoretical development in this area (Staniszewska and Henderson 2005). Many areas of the NHS developed patient feedback questionnaires and at a national level the National NHS Patient Survey was implemented (Picker, 2002) for adult patients. Initially this

survey only involved adult patient views and excluded from the survey were some patient groups where it was considered more difficult to access their opinions, for example, patients with a learning disability and mental health problem. Similarly, children and young people and their parents were initially excluded from the survey. Various reports highlighted inequity for young patients by their exclusion from the patient survey (LaValle et al, 2012; Lewis and Lenehan, 2012) leading to changes, and this has now been addressed.

The effectiveness of patient satisfaction surveys has been questioned (Williams et al 1998) as many believe that they do not present a realistic picture as the tendency has been production of overwhelmingly positive results. The face validity of these results is questioned as this does not seem to truly reflect public opinion of the NHS which is expressed in the media and in everyday life. Reliability and validity of the patient survey perhaps became more critical when financial rewards for hospital Trusts based on survey results were first announced (DOH, 2000a section 10.24). The DOH (2000a) declared that the survey had been devised and refined and provided a robust tool to capture the views of the service users. The survey was devised to look at specific elements of patient experience rather than satisfaction in recognition of the problems with this area. Interestingly, this has now moved on to include a 'recommendation to friends and family' test within the survey.

Dissatisfaction and Complaining

The Parliamentary and Health Service Ombudsman produces an annual report which draws attention to the unresolved complaints about health care that the

Ombudsman has investigated and makes recommendations for service improvements from these cases (Parliamentary and Health Service Ombudsman, 2016). Whilst many of the examples cited within these reports are extreme and tragic cases there are also recurrent issues which appear year on year. Examples of issues which regular feature in these reports on health care include poor communication with patients and families, poor attitudes of staff and negligent care. The Ombudsman acknowledges that for the vast majority of patients and their families their NHS experiences are rated positively and they value the services provided for them.

In comparison to the number of patients treated in the NHS each year formal complaints are still relatively low overall and the numbers decrease substantially if only complaints about children's health care are examined (Parliamentary and Health Service Ombudsman, 2016). There are a couple of ways of interpreting such information:- one is that the health care provided is of a high quality and therefore levels of complaint are low or patients, parents or carers are reluctant to formally complain about care. It is interesting to consider again the similarities and differences with the retail world and patients or parents of young patients in health services, this time in relation to complaint behaviour.

Research evidence within the retail sector is both limited and dated, however, studies have shown patterns of consumer reluctance to complain have previously been reported (East et al, 2008). Level of dissatisfaction equated to probability of complaints (Oliver 1987; Singh and Howell, 1985; Malafi et al 1993) but other influential factors included the importance of the product (Richins, 1985), consumer's view of cause of problem, personal costs of complaint, convenience and awareness of process and their belief that

complaining would improve the situation (Grønhaug, 1977; Day 1984; Singh and Howell 1985; Richins, 1987; Singh, 1990). East (2000) used Ajzen's theory of planned behaviour (Ajzen, 1985, 1991) to explore complaint behaviour and found motivation to complain related to:- obtaining a refund or replacement, standing up for one's rights, doing what friends expected and confidence about complaining. In Ajzen's Theory of Planned Behaviour (Ajzen, 1985, 1991) the normative influences were considered to be what people think other key groups or individuals may think their actions should be whereas control factors were factors which enabling or preventing complaints. Control factors in complaint behaviour included the individual's knowledge, skills, time, accessibility of key staff, understanding of the organisation's processes and confidence about complaining (East et al, 2008). Non-complainers were generally those who felt powerless; were less knowledgeable of redress; were more vulnerable e.g. the elderly, ill and disadvantaged (Warland, Herman and Willits, 1975; Andreasen and Manning, 1990). Limited sense of control in these groups and possible low levels of expectations may account for these findings.

Consumer complaints are viewed as valuable in retail and business contexts as this enables further product and service development to meet customer need and expectation (Fornell and Wernerfelt, 1988). Complaints can be seen as a way of collecting important data about products that can then put companies ahead of competitors. Effective handling of dissatisfied customers has been recognised as critical for success. A phenomenon known as the Service Recover Paradox (De Matos et al, 2007; TARP, 1979; Gilly and Gelb, 1982) has been described whereby customers retained after a complaint was resolved were often more satisfied than they would have been without the problem

occurring. It is thought that this happens when the complaint is well-handled, resolves the dissatisfaction and exceeds expectations. An alternative perspective on this is that customers whose intention was to stay with the company complain in order to benefit from changes resulting from their feedback. Magnini et al (2007), found that the Service Recovery Paradox occurred in situations where the problem was not considered too bad, where this was a first problematic encounter with a company, the reason for the problem was considered "unstable" or where the customer perceived that the company had little control over the problem. Perhaps the variance of Service Recovery Paradox and levels of satisfaction for differing services relate to the importance of the service or goods to the customer. Interestingly in the United States, Solnick and Hemenway (1992) reported that people who complained about health care were over four times more likely to move to a different provider than others. Clearly this is within the United States system where individuals have some degree of choice about their health care provider but nevertheless the stark difference between customer complaint behaviours when dissatisfied with goods and services (Gilly and Gelb, 1982) compared with aggrieved patients is well worthy of note. This does suggest that people do act differently when they are customers compared to healthcare service users and the higher stakes associated with their health care may well account for this difference.

There are some interesting debates with regard to service quality and customer satisfaction. It is recognised that service quality can be challenging to define and measure and that perceived service quality is a type of opinion or view related to but not the same as customer satisfaction. However, some

researchers (Bitner et al, 1990; Bolton and Drew, 1991; Parasuraman et al, 1988) see customer satisfaction as preceding service quality and others (Hoisington and Naumann, 2003; Spreng and Mackoy, 1996; Woodside et al, 1989; Lee et al, 2000) believe that it is in fact quality that leads to customer satisfaction. The research evidence mainly supports the view that service quality is a precursor to customer satisfaction (Cronin and Taylor, 1992; Dion et al, 1998; Lee et al, 2000). The difference between the customer being satisfied and the quality of the goods and services provided is of importance to companies as they can then decide the best strategies to achieve i.e. customer satisfaction or the perception of quality services and products. The subtle differences between the two and the issues that surround these debates are important in the business world as they may affect sales and ultimately this is the key focus and motivation of all businesses.

Changing nature of the patient population

In the business world, consumer behaviour can be anticipated on the basis of consumer attitudes, values and beliefs as well as their previous behaviours (Ajzen, 1991) and these ideas have shaped the availability of products and services to fit the customer's changing wishes and needs. In business, matching expectations and needs with products and services results in financial profits for organisations; however, in the NHS, growing patient expectations and demands of the service have to be met within the financial constraints of the service which can be challenging. Some of these challenges are raised within the findings of a large complex study (Laing et al 2010) that examined the impact of the internet on patient and health care professional inter-actions.

Three main themes emerged from the data:- the notion that patients' expectations and behaviours have become increasingly diverse and the gap between their expectations and behaviours is wider than in the past. This study recognised that a variety of different types of patients currently exist which Laing et al (2010) refer to as the range of informationally empowered patients and noted that all types of patients displayed variation in the way in which they engaged with professionals and used information. It was recognised that whilst the internet can offer the opportunity for patients to access information that was previously the preserve of the professionals, this also presented challenges for patients. The pros and cons of internet information had to be weighed up by the individual in terms of their own situation before making their decision about searching the internet. The diversity of patient behaviours was captured within the Service Consumption Typology (Laing et al, 2010) which was constructed from the data and reflected the consumer attitude towards health care professionals and their behaviours during interactions with them. Attitudes of patients to healthcare professionals ranged from *convinced* through to *sceptical*, whilst their behaviours were seen as being on a continuum from *passive* to *active*. The typology identified four main types of patients: compliant sceptic; compliant convinced; active sceptic and active convinced. Amongst convinced patients there is an acceptance of conventional medicine and the professional integrity of the clinician to provide appropriate care. The more sceptical patients, are more questioning of medical practice and do not anticipate that the professional will necessarily act in their best interests. In considering the behaviour types of the patients, it was noted that those at the active end of the spectrum were assertive and challenging to professionals within interactions. Those at the compliant end of the spectrum were seen as accepting and

obedient or even submissive. Information seeking behaviours also differed amongst the four types. Active sceptics were consistently seeking information whilst the compliant-convinced patients at the opposite end of the scale were low level information seekers.

The typology was used to explore the divergent informational and encounter preferences of discrete groups of patients in the study. Laing et al (2010) recognised that there was a growing gap between expectations of certain categories of patients and the prevailing professional discourse and suggested that where mismatch was increased the likelihood was that the patients would be dissatisfied with the service and consider the service to have failed them. They identified that active patients would expect to have choice: accepting that this brings with it uncertainty to some extent. The active convinced patients would mainly gain information from health care professionals and would self limit the use of the internet. The active sceptics posed the biggest challenges as they expected choice of alternatives and engagement beyond usual discourse with the professionals. They may seek collaboration with the professional in an egalitarian way confirming information that they have discovered and bringing with them an expectation to engage beyond the normal core discourse. Convinced active and compliant patients are likely satisfied with current medical discourse as their attitudes and behaviours were better matched to existing discourses.

In the past, patients' attitudes and behaviours within their interactions with clinicians were perhaps less diverse than they are today. Laing et al (2010) point out that the diverse and fragmented patient population that now exists

produces a whole host of challenges for professionals aiming to meet their service encounter requirements. They conclude that delivery of service to this fragmented population in a single 'one size fits all' approach is not likely to satisfy or meet patient expectations but to provide a more customised service may not be feasible given service constraints. Laing et al (2010) also raise issues about the core drivers of the health service in terms of equity and public benefit and how creating bespoke service to individuals may conflict with the core principles given resource limitations.

Laing et al (2010) commented that these issues,

"...raised basic questions about the nature of public service provision in contemporary societies and ultimately in such a setting the boundaries to patient sovereignty" (2010, p189).

This comment highlights the challenges in pursuing a personalised and consumer based approach to health services and questions whether some parameters to this notion need to be put in place. The comments made here by Laing also plays on the words used as a regular mantra used in business and retail that the "customer is king" and suggests that such sovereignty in health care may not be limitless given the competing demand to provide equitable care for all. Clearly, patients' perspective on quality of care is of great importance and in children and young people's hospital care there is now recognition of the need to understand the young patients' perspective and experiences to develop health care services. At the same time, parents have a critical and unique role when their child is in hospital and their perspectives and experiences are equally vital in the quest to improve care through analysing and understanding

their experiences. This is not as a proxy for their child's experience but from their own perspective as for younger children they are in the privileged position of having responsibility for their child, making decisions on their behalf and whilst their child is hospitalised they will witness or participate in care and should receive care and support themselves from staff.

Structure of thesis

An outline of the structure of the thesis is provided here for guidance. The thesis is divided into eight chapters followed by references and appendices.

Chapter 1 Introduction

This chapter opened by presenting the rationale for the focus and direction of the study including details of its origins. Personal experiences in nursing and research which may have influenced topic choice and approach were also provided. Key terms and concepts central to the research have been defined and discussed i.e. quality, care, family-centred care, judgement. A brief historical overview of quality improvement strategies adopted by the NHS over the years was presented alongside an overview of the business and retail world's approaches to quality. The changing position of patients as they became viewed as service users has been acknowledged, although the notion of these 'consumers' of health care and consumers within the business or retail world as being comparable was challenged. These discussions have provided the backdrop for the exploration of parents' perspectives of the quality of their

child's hospital care. The chapter concludes with this outline of the chapters within the thesis.

Chapter 2 Literature Review

An initial brief literature review was undertaken at the outset of the study followed by a more extensive review latterly. However, the reviewed literature is provided within chapter 2 to enable the reader to appreciate the existing research literature prior to presentation of this study and its findings. The review and critical synthesis of the research evidence relating to parents' and children's experiences of hospital care and quality of care, and health professionals' perspectives is provided in this chapter. The aim, design and the methods employed are outlined first, then the key themes are presented in three sections - parental, child and health professional's perspectives. Key themes which emerged within the parents' perspectives included: satisfaction with care; communication and interactions; emotions; involvement in care; queries and concerns. The themes identified within the review from the children's perspectives included: communication; emotions; involvement in care; environment; health professionals. The themes within the studies reviewed from the health professional perspectives included: beliefs and perceptions; roles and relationships; power and control; difficulties in implementation of family-centred care. This review of the literature identifies some similarities but also variations within the three perspectives and areas where there are gaps in existing knowledge.

Chapter 3 Methodology

This chapter identifies the research paradigm within which this study is set as interpretivist and critically discusses its philosophical underpinnings in comparison to other research approaches. The rationale for using a constructivist grounded theory approach is provided and the epistemological and ontological stances are explored. Historical development of grounded theory is outlined and the different schools of thought within this methodology are critically discussed.

Chapter 4 Methods

Ethical issues relevant to the conduct of this study are outlined and form the foundation on which the research was carried out. This chapter provides details and critique of constructivist grounded theory methods and their application within this research study. The study's setting and the sampling and recruitment strategies are presented and key aspects of the processes used within the study are critically discussed including theoretical sampling; theoretical sensitivity; data analysis; memoing and theoretical saturation. The details presented in this chapter provide an audit trail of the decisions made as the study progressed thus evidencing trustworthiness and rigour.

Chapters 5, 6 and 7

These three chapters detail the findings from which the grounded theory was constructed.

Chapter 5 Landing in an alien world

The core category, 'on guard and on behalf' of their child, was constructed from analysis of parents' experiences of their child's hospital care and is identified in this chapter. It focuses upon appreciation of parents' evaluations and subsequent responses to these experiences motivated by their primary concern of protecting and advocating for their child in the unfamiliar world they find themselves in. This core category is central and underpins and is connected to all other categories established. The usual world in which parents normally protect and advocate for their child is acknowledged here as the family find they have moved from their 'outside' and familiar world to the very different and unfamiliar world of the hospital. The emotional impact and shock of their child's hospitalisation is apparent in the parents' narratives reported in this first findings chapter. The gratitude and relief for some parents whose child's admission is a short and one-off experience is evident as they return to the familiar outside world. Parents who had lengthy or regular experiences within the hospital became more accustomed to the hospital and their accounts continue in Chapter 6.

Chapter 6 From 'new parents' to 'old hands'

In this second findings chapters the transition, from being parents unfamiliar with hospital care to parents familiar in this world, are presented. The personal lens through which each individual parent views and makes sense of the situation is constructed from their past experiences, personal beliefs and

values. The differences in parents' behaviours as they became more experienced within the hospital are recounted in this chapter. The strategies parents used to manage some of the tensions and disruptions that their child's hospitalisation caused within family life are evident in their accounts. During the transition from being 'new parents' to 'old hands' personal perspectives were often altered as parents made sense of the situations themselves or were supported by health professionals to do this.

Chapter 7 Parental judgements and responses

In this final findings chapter the way that parents made judgements about the clues they discovered and parental responses to issues of concern to them are recounted. In addition, findings from the data regarding the way that parents chose to raise queries and concerns with professionals is presented. The parents accounts describe their dilemmas and choices in the level of their response when they have a query or concern about their child's care. Finally, the variance between the 'at the time' and the moderated and more positive 'on balance' judgements of quality of care are described.

Chapter 8 Discussion and Conclusions

The grounded theory constructed within this thesis presents some new perspectives on the complexities of the psychosocial processes that underlie parents' expressed judgements of the quality of their child's hospital care. In this final chapter, the emergent theory is explored alongside relevant aspects of the

existing literature to demonstrate areas which provide a unique contribution to the knowledge base.

Within this final chapter this new theory is evaluated in terms of work, fit and modifiability. The implications for children's health care policy, practice and education from this study's findings are also considered. In addition, there is discussion of further research work that could be undertaken to extend and develop the insights this study affords within children's care but also to explore transferability to other groups and settings.

It is envisaged that the findings from this study will be helpful to health care professionals in their day to day exchanges with parents and may enable them to further enhance the way they anticipate and respond sensitively and effectively to parents in the future.

Conclusion

In this first chapter the aim has been to set out the rationale for undertaking the study and to provide background and contextual information. A brief summary of each chapter has been included to help guide the reader through the thesis from its inception through to the construction of the grounded theory.

The next chapter will discuss the research literature in relation to key perspectives of quality in children's hospital care thus grounding the research in existing knowledge and identifying potential gaps in this knowledge.

Chapter 2 Literature Review

Introduction

The background and context to parents' experiences within today's health service was provided in chapter 1, alongside discussion of quality improvements within the business and retail world. The adoption of these quality improvement approaches within health care was also explored, in recognition of their importance as a backdrop to examining parental quality evaluations of hospital care. It is important now to consider the research literature regarding parental, child and professional perspectives of quality in children's hospital care. In this chapter, the review's aim and methods are detailed, then findings are presented under the following sub-headings:

Parental perspectives:

- satisfaction with care
- communication and interactions
- emotions
- involvement in care
- queries and concerns

Children's perspectives

- communication
- emotions
- involvement in care
- environment
- health care professionals

Health care professionals:

- beliefs and perceptions
- roles and relationships
- power and control
- difficulties with family-centred care

Discussion and conclusions

There are different views of the approach to be taken with regard to the use of the literature review in initial stages of a grounded theory study (Birks and Mills, 2011). Delaying the literature review in grounded theory is accepted as a means of limiting the extent to which previous theory and knowledge influences development of the grounded theory. In the early years of grounded theory there was acceptance that all researchers would enter the field with some prior knowledge (Glaser and Strauss, 1967) and although Strauss and Corbin (1990) continued to support this notion, it appears that they did not guide researchers away from key literature in the early stages in the way that Glaser felt they should have done. Glaser's (1992) reaction was to urge researchers to completely avoid the literature in the subject area to avoid affecting the analysis. In reality, both positions share key beliefs that there is an acceptance that researchers will have an existing knowledge of the topic to be explored and a full review of the literature is not supported in the initial stages when undertaking grounded theory (Birks and Mills, 2011).

In this study, the literature was considered briefly initially but was re-visited more thoroughly latterly and is reported on in this chapter. The literature review design and methods employed are outlined first, then key themes emerging during critical synthesis of the research studies are presented in three sections - parental, child and healthcare professional perspectives. Exploration of quality care from these key stakeholder viewpoints supports the over-arching aims of the thesis by providing a review of existing evidence in this field.

Aim

The aim was to review and critically synthesise research evidence on parents' and children's' experiences of hospital care and quality of care, and health professionals' perspectives.

Review methods

A structured review of the literature was undertaken to retrieve relevant research studies published in academic journals between January 2000 and December 2015. Primary research studies were included or excluded on the basis of the following criteria:

Inclusion criteria

- Studies focused on parents', children's or health professionals' experiences of children's hospital care and their perspectives of the quality of care
- Studies published in English Language and originated from developed countries

Exclusion criteria

- Studies with a focus on palliative; end of life care; quality of life care and safeguarding.
- Individual case studies
- Studies where the focus was on care delivered in the community, intensive care units, oncology units, neonatal or maternity units.

The inclusion and exclusion criteria were designed to retrieve the most relevant research studies that focused upon children, parents' and health professionals' experiences and perspectives of quality hospital care. The inclusion of studies from developed countries meant that research studies reviewed were more likely to have been undertaken within countries with similar health and social care settings to the UK. The exclusion criteria identified some specific care and care settings, for example, intensive care and palliative care where the needs of the children and families were likely to be significantly different from general children's hospital care which was the focus of this thesis.

Studies were identified by searching three health and social science databases, CINAHL, MEDLINE and PROQUEST which provide indexing of qualitative and quantitative studies on a wide range of topics relevant in health care. A fifteen year period, January 2000 - December 2015, was chosen because studies within this time frame were more likely to reflect comparatively recent health policy, practices and care delivery within developed countries and recent expectations of service users and professionals. Key terms used to search for relevant research studies included:

mother*; father*, maternal; parent*; child*, young patient*, service-user*, nurs*, doctor*, clinic*, health care professional*, health professional*, hospital care, hospital experience, hospitalisation, hospitalization, paediatr* hospital care, pediater* hospital care, care, paediatr* healthcare, health care, service, family-centred care, family centred care, family centered care, experience*, quality, judgement*, evaluation*, opinion*, perception*, perspective*, satisfaction.

These terms were used in a range of combinations to enable the search to be inclusive initially then increasingly focused and limits were then applied with regard to publication dates (January 2000- December 2015), location (developed countries) and language (English Language). An illustration of the search strategy to retrieve relevant literature is presented in Table 1.

Table 1. Example of combined Cinahl and Medline search relating to parental perspectives of quality of child's hospital care (January 2000- December 2015)

Search ID#	Search strategy	Results
S1	parent*	89,282
S2	mother*	50,358
S3	father*	8,355
S4	Maternal	70,188
S5	Paternal	3,608
S6	S1 or S2 or S3 or S4 or S4 or S5	214,662
S7	child* hospital care	10
S8	Care	587,319
S9	paediatric care	176
S10	pediatric care	527
S11	child* hospitali*	876
S12	child* health care	878
S13	child* healthcare	144
S14	child* health service	659
S15	child* hospital service	7
S16	S7 or S8 or S9 or S10 or S11 or S12 or S13 or S14 or S15	588,891
S17	evaluat*	477,128
S18	Satisfaction	28,608
S19	perception*	73,356
S20	experience*	239,400
S21	judgement*	2,197
S22	perspective*	119,711
S23	view*	81,395
S24	S17 or S18 or S19 or S20 or S21 or S22 or S23	1,005,279
S25	Quality	201,064
S26	S6 and S16 and S24 and S25	92
S27	S6 and S16 and S24 and S25 Limiters - publication date 05-15.	53
S28	S6 and S16 and S24 and S25 Limiters - English	47

The initial electronic database searches yielded 3,122 records; each title was quickly examined to establish if the study related to the review focus; following exclusions 284 records remained. Hand searching of key journals was undertaken for the periods of 2010-2015 - these included the Journal of Advanced Nursing; Journal of Child Health Care and Child: Care, Health and Development to optimise retrieval of relevant studies. The bibliographies of key papers were also reviewed to check for additional studies for inclusion. A further 7 studies were included from the hand-searching. Abstracts of papers identified through database searches and hand-searching were screened to identify if the inclusion criteria were met. In total 46 papers were included in the review: 27 included parental perspectives; 18 included children's perspectives and 13 included health professionals' perspectives. It should be noted that 10 studies were included in more than one grouping as they contained more than one stakeholder's perspective. The quality of the papers for inclusion were assessed against predetermined criteria using appropriate qualitative and quantitative evaluation tools - Critical Appraisal Skills Programme (CASP) Qualitative Tool (www.phru.nhs.uk, last accessed 10.9.15) (see Appendix 1) and McMaster quantitative review form (www.srs-mcmaster.ca/research/evidence-based-practice-research-group, last accessed 20.12.15) (see Appendix 2). All papers included in the review were published in peer reviewed journals and whilst the quality of studies varied none were assessed as requiring exclusion on the grounds of poor quality. A scoring system was devised to provide numerical representation of the quality of reviewed papers and a summary of these quality appraisal scores is provided in Appendices 3 and 4. Scores of 0-2 were awarded for responses to each question within the critical appraisal tool: 0= not detailed/achieved; 1=partially

detailed/achieved; 2= fully detailed/achieved. The range of possible total scores for the CASP tool was 0-20 and the McMaster's tool was 0-16. The reviewed qualitative papers scored between 15 and 19, from a possible score of 20 and quantitative papers scored between 13 and 15, from a possible score of 16. Overall, both qualitative and quantitative studies were of good quality, appropriately designed, undertaken in an ethical way and, despite varying limitations, all papers produced useful knowledge within the subject area. The quantitative studies mainly used survey designs guided by established quality measures and accessed large samples of parents, children and health care professionals. Whilst surveys were effective in accessing the views of large samples quickly, it was often difficult to assign meaning to participants' responses due to their brief nature, thus limiting their value. Most of the qualitative studies were relatively small in size and reported sampling limitations related to difficulties recruiting from all socio-demographic groups particularly with regard to participants who did not speak the native language of the researchers. Despite these limitations, the studies produced some insightful findings and uncovered some important perspectives relating to quality of children's hospital care.

Characteristics of the studies reviewed, including location, sample, type of hospital experience/child's condition are summarised in tables within Appendix 3, 4 and 5. Design of the studies reviewed, including purpose of study, sampling, methods and key findings are summarised in tables within Appendix 6, 7 and 8.

The findings from the review will be presented here in three sections:- parents' perspectives; children's perspectives and health professionals' perspectives. The chapter then concludes with discussion and conclusions from the review.

Parental perspectives

The majority of studies reviewed focussed on parents' experience of their child's hospital care but few set out to specifically explore parental judgements of the quality of their child's care. However, through analysis of parents' experiences aspects of care valued by parents were uncovered. The strict inclusion exclusion criteria for the review meant that many studies were excluded despite focusing on parental experiences or quality of care and this was due to the specialised nature of their care focus, for example, end of life care and intensive care.

Key themes that emerged from the included studies were:-

parents' satisfaction with care; communication and interactions; parents' emotions; parents' involvement in care; parents' queries and concerns.

Parents' satisfaction with care has been selected as the most appropriate theme to begin the literature discussion since findings within this theme provide some over-arching messages from studies and generic background to parent's perspectives of key aspects of quality care. Subsequent themes provide more in-depth knowledge of specific aspects of parents' experiences and together build a picture of the main messages from research within this field.

Parents: satisfaction with care

Several studies that provide parental evaluations of their experiences of their child's hospitalisation have utilised quantitative designs and focus upon satisfaction ratings for various elements of the care experience. These studies provide some interesting and important information about how parents rate care but are not able to provide further in-depth explanations for parental responses.

Although there were many differences in the survey designs, variation in sample sizes, content of the questions and the countries in which the studies were undertaken, some universal messages were evident. Parents positively rated their child's care when they felt there was sufficient information and communication provided (Co et al, 2003; Matziou et al, 2011; Byczkowski et al, 2013); they had opportunity to have their questions answered (Ammentorp et al, 2006); they perceived care to be well co-ordinated (Co et al, 2003); concerns and complaints were resolved (Miceli and Clark, 2005) and nurses and doctors worked well together (Byczkowski et al, 2013). Again, although expressed differently within the surveys, nurses' and doctors' behaviour, the quality of pain management, clinical/medical care and treatment were all found to be important factors in parental satisfaction with care (Simons, 2002; Ammentorp et al, 2006; Matziou et al, 2011; Byczkowski et al, 2013).

In one study of surgical care experiences (Simons, 2002), parents expressed greater satisfaction with care when their child was looked after by lower grade nurses and researchers found that children received more analgesia when they were nursed by lower grade rather than higher grade nurses and more pain

assessments and analgesia was administered in children over five years. This study used both qualitative and quantitative methods to explore nurses' and parents' perceptions of support and parents' satisfaction with their child's post-operative pain management. A phenomenological approach was taken within the interviews; surveys were used to collect data using a questionnaire, the Nurse Parent Support Tool (Miles et al, 1999) and documentation was reviewed for pain-related data. The sample (*n*-20 nurses and *n*-20 parents) were matched so that nurses who mainly cared for the child and the parents' data could be compared. This study (Simons, 2002) was part of a larger study and due to the limited details regarding sample recruitment and selection it is not possible to determine the types of surgery the children underwent, any variations in length of stay, age of the children or whether they had chronic conditions in addition to their need for surgery.

The limitations in the information provided about the sample mean that some caution needs be taken when interpreting the findings. However, paired data comparison of the nurses involved in the child's care and their parents is a strength of the study and enables similarities and variances in perspectives to be examined.

In reporting on the findings that lower grade nurses gave more analgesia than higher grade nurses, the researchers' interpretation was that lower grade nurses were more able to focus on direct care than higher grade nurses who may have had other duties and responsibilities. However, these differences may equally be explained by variance in sensitivity to children's pain associated with experience, so rather than being more empathetic to children's individual pain levels, senior nurses may have anticipated a child's pain level based on their own experiences of other children who have undergone the same

procedure. Twycross (2007) has previously commented that the influences on poor pain management practices by nurses may include professional or ward culture, nurses' beliefs and attitudes, in addition to prioritisation and knowledge of pain management. It is possible that lower grade nurses in Simons' study (2002) did not hold fixed views or beliefs about children's pain nor been schooled into the prevailing ward culture, in terms of the usual administration of analgesia and therefore, responded directly and more effectively to the child's individual pain reports which, in turn, was appreciated by the parents. Similarly, there was an apparent bias by the nurses to managing pain in older children. The bias may be due to nurses behaving as if all children are at a stage of logical thought thus understanding cause and effect, an observation also previously noted by Twycross (1998). However, such bias may equally be due to underlying and unacknowledged beliefs that younger children feel less pain which may be re-enforced though misinterpretation of young children's behaviours suggesting that they are not in pain e.g. because they are playing or sleeping.

Nursing staff are often the health professionals who have most opportunity to interact with parents when their child is hospitalised and parental satisfaction may be influenced by these interactions with nurses. Equally the extent to which parental expectations are met may influence their satisfaction. Espezel and Canam (2003) undertook a study to explore parental experiences of parent-nurse interactions when their child was hospitalised. This qualitative study employed in-depth interviews to collect data from a purposive sample of parents ($n=8$) of children who were born extremely prematurely or had suffered neonatal critical illness resulting in on-going medical problems requiring monitoring and

often lengthy hospitalisations. The relatively small number of interviews undertaken may be seen as limiting in terms of development of themes and potential transferability of findings. However, purposive selection of participants ensured those included were key informants enabling researchers to gather rich data about the phenomenon critical to the study. Researchers demonstrated rigour within the study through explanation of the research audit trail which included, detailed records of the study's progress from origin of the research questions through each stage of data collection and analysis. Reflective journals were used to uncover personal bias and an open approach to interviewing was adopted to optimise candid accounts from the parents. These steps provide some assurance of the trustworthiness and confirmability of the findings. Main themes identified from the data relating to effective parent-nurse interactions from parental perspectives were the establishing of rapport and sharing of their child's care, both of which were influenced by the parental expectations. Parental expectations of nurses were found to be influential within interactions and parents reported differences in nurses' behaviour dependent on their child's condition. Parents positively commented on nurses' interpersonal skills and the way that nurses acted as translators for them when doctors provided information that they could not fully understand (Espezel and Canam, 2003). Parents' comments suggest their expectations of nurses and doctors differed which may have influenced their overall satisfaction with care. Medical staff were found to be measured by their level of competence, clinical outcomes and the parents' confidence in them rather than on their compassion, interpersonal or communication skills. In contrast nurses were expected to be effective communicators, demonstrating caring and compassionate behaviours and were measured against these criteria (Espezel and Canam, 2003;

Ammentorp et al, 2006). These different sets of expectations and corresponding levels of parental satisfaction are interesting as they demonstrate to some extent the principles of consumer satisfaction with products and services explained within the confirmation/disconfirmation models discussed earlier (See Chapter 1). Applying these models to the parents' experiences it is evident that low levels of expectations, for example, of medical staff as communicators may merely confirm their expectations, therefore, ratings may remain satisfactory whilst for nurses the same level of performance as communicators may be rated as less satisfactory due to parental expectation levels. The impact of personal beliefs and expectations on parental satisfaction with care ratings may be only one of several psycho-social factors influencing the judgements underlying parental responses and this is an area which is not yet fully understood. The reasons for particular parental satisfaction ratings with regard to some aspects of care appear paradoxical, for example, Ammentorp et al (2006) found that shorter waiting times were preferred by parents and were frequently mentioned by parents when asked about their experiences but this element of the experience was found to be a weak predictor of overall satisfaction with care.

There has been limited exploration to determine if variance in satisfaction with care ratings correlate with differences related to the parents themselves. Only two studies (Ammentorp et al, 2006; Solheim and Garratt, 2013) within this review collected data to examine these associations. Ammentorp et al (2006) found socio-demographic characteristics of parents to be a poor predictor of parental satisfaction levels within their study of parents within an acute in-patient unit in Denmark. This was a descriptive quantitative study which used

self-administered questionnaires to identify parental expectations and priorities prior to hospitalisation and then experiences and satisfaction following hospitalisation. A convenience sample of 300 parents of children admitted with acute illness, during the day/evening within a two month period and who could speak and understand Danish were enrolled within the study. This study produced important findings demonstrating some key determinants of satisfaction and as previously noted some discrepancies between parents' identified priorities and their final satisfaction scores. The findings are important but need to be viewed with some caution in terms of their generalisability due to the relatively small sample drawn from one centre which may not be representative of the country's population. Parents from immigrant groups may have been excluded due to the language requirements thus further limiting representativeness of the sample. The quantitative survey design used within the study did not provide opportunity for exploration of any underlying reasoning for apparent mismatches of parental priorities with their satisfaction ratings so it is not possible to fully understand from parents' perspective why this may have occurred. One interpretation of these findings may be that the experience of hospitalisation itself may alter a parents' priorities within care provision.

The second study to consider socio-demographic factors impacting on parents' experiences of their child's hospital care was a large national study undertaken in Norway (Solheim and Garratt, 2013). Data was collected through the Norwegian national survey of parental experiences of in-patient children's care and was sent to 6,160 parents, 3,308 (53.8%) parents responded. The large and representative sample and satisfactory response rate for such a survey generally supports the validity of the study's findings. Overall, findings indicated

little significant variation in parental experiences associated with different socio-demographic groups. An association was reported between parents' education level and dissatisfaction related to organisation but this was reported as a weak relationship. Lack of correlation between differences in satisfaction and parents' socio-demographic characteristics were thought to be due to the universal access to services offered within this country. Parents in employment were, however, found to report experiences more negatively compared to parents who belonged to potentially more marginalised groups, for example, those with low incomes, disabilities or poor health. The researchers thought these results were surprising but these findings may have resulted from different parental expectations within the groups, variance in how empowered the parents may have felt to express negative viewpoints, differences in how parents viewed their right to the services or possibly even their gratitude for these services. Gratitude for care provision, even when care has been less than optimal, has been previously identified as an influencing factor in adult patients' positive evaluations of quality of care in the UK (Staniszewska and Henderson, 2005). Potential for such underlying psycho-social factors to influence expressed opinions of parents has not been fully explored within the literature relating to parental perspectives and is an area that needs to be better understood to enable effective quality improvements to be made.

Although socio-demographic variation in parental satisfaction ratings was not found to be a focus within the other reviewed studies, differences between satisfaction levels of parents of children with special needs when hospitalised compared with parents of other children has been examined (Phua et al, 2005). Phua et al (2005) set out to evaluate parental perceptions of in-patient care for

children with cerebral palsy in comparison to other parents using a self-administered questionnaire and scale to measure perceived stress levels - the Perceived Stress Scale (PSS-10) (Cohen et al, 1983). Convenience sampling was used to recruit two samples, parents of children with cerebral palsy ($n=40$) and parents of able-bodied children ($n=90$). The sample size was determined appropriate through the use of power calculations from an initial pilot study. The sample size was identified to have 85% power to detect a 20% difference in overall scores of the questionnaire with a p -value of 0.001 which provides confidence in the size of the sample recruited. The researchers supported the reliability and validity of the data collection tools used by detailing the extensive work undertaken in questionnaire development with key informant involvement and piloting, similarly, the PSS-10 (Cohen et al, 1983) was reported to be a validated tool recognised for its good internal reliability, factor structure and ability to predict outcomes. Findings indicated that parents of children with special needs were found to be more dissatisfied than other parents with a range of elements of care, for example, comfort, hospital toy provision, meeting hygiene needs, perception of timeliness of medical responses, consistency of medical care, doctor's communication and how well acquainted staff were with their child's individual needs. These parents also felt they had less confidence in nursing staff than parents with able-bodied children. Researchers acknowledge that there were some differences between the two samples that need to be considered when interpreting the results: the children with cerebral palsy were generally older and had more hospital experiences than the other children; different medical teams were involved and severity of illnesses may have affected outcomes. Another confounding factor identified was the length of stay in relation to completion of the questionnaire with the possibility that

there may be growing dissatisfaction with passage of time. However, differences between both groups was found to continue regardless of date of completion of the questionnaire. Various explanations may be offered for the findings, for example, parents of children with special needs may be more dissatisfied because care and resource provision may not actually meet their child's particular needs in the way that it does for a child without any additional needs. Alternatively, these findings may reflect differences in levels of parental expectations or perhaps, parents with more frequent hospital experience may be less tolerant of shortcomings in care than other parents who may only have short, one-off exposure to hospitalisation. Lack of tolerance of such problems may also reflect the existing daily burden of care and additional stresses of caring for a child with special needs as reported by Avis and Reardon (2008). In addition, the repeated nature of their hospital experiences may further impact on their decision to provide less positive ratings in the hope that this will stimulate changes in provision. If this were the case then this behaviour would mirror some of the described consumer complaints behaviours, discussed earlier (chapter 1) whereby customers reported feeling they should complain about faulty goods or poor service in order to stimulate beneficial changes for themselves or future customers.

Communication and inter-actions with professionals was another recurrent theme within the reviewed studies and its importance for parents and children was evident. In this next section this theme will be considered in more detail from the parental perspectives and later the children's perspective will be discussed.

Parents: Communication and interactions

Communication and interactions with professionals emerged as important aspects of parental experiences of their child's hospitalisation. Parents expected to receive information from professionals about their child's condition and care in hospital but these expectations were not always fully met (Stratton, 2004; Coyne and Cowley, 2007; Matziou et al, 2011; Solheim and Garratt, 2013). Effective interactions with professionals and information provision were found to be important features of overall parental satisfaction when parents were asked to rate various aspects of their experiences of their child's hospitalisation (Miceli and Clark, 2005; Matziou et al, 2011; Byczkowski et al, 2013; Solheim and Garratt, 2013). Parents needed a range of information from health professionals to help them understand and cope with their child's hospitalisation and these needs were met to varying degrees and this was reflected in overall parental satisfaction with care.

Parents wanted to know about the hospital environment and processes to enable them to orientate themselves within the setting. Williams et al (2011) suggested that parental information needs related to ward routines, for example, awareness of ward rounds, knowledge about which doctors and nurses were responsible for their child's care and who they could direct their questions to about their child's condition and care. However, survey data relating to parental satisfaction within U.S. hospitals highlighted parental information needs regarding some basic facilities, for example, places to sleep, talk, shower and eat (Miceli and Clark, 2005). It appears that where parents perceived a lack of information existed, be it about ward routines or facilities,

parents may feel dissatisfied with care (Williams et al 2011; Miceli and Clark, 2005).

Other researchers (Stratton, 2004; Coyne and Cowley, 2007) proposed that parents needed explanations as well as information and direction by nurses in relation to their child's care and that information and explanations needed to be provided simply and without jargon (Sartain et al 2001; Stratton, 2004). Stratton (2004) suggested that parents needed to be kept informed about what was happening with their child and what they needed to do in relation to care-giving for their child. It has been suggested that where parents felt such information and explanations were not forthcoming this affected parents' sense of well-being (Stratton, 2004) and contributed to parental anxieties (Coyne and Cowley, 2007).

Another important area of information provision for parents related to information about their child's diagnosis and treatment. Findings demonstrated parental dissatisfaction when they perceived the information provision to be poor regarding their child's illness, prognosis, diagnostic tests, results and treatments (Matziou et al, 2011); new medications for their child (Solheim and Garratt, 2013); or their child's diagnosis (Sartain et al, 2001). In contrast, some parents felt they were kept informed about their child's condition and progress (Sartain et al, 2001; Stratton, 2004) and were satisfied with the level of information provided about facilities; hospital routines and their child's condition (Sartain et al, 2001; Stratton, 2004 Matziou et al, 2011). Parents valued health professionals that kept them informed about their child even when there was uncertainty for the professionals themselves (Stratton, 2004). When parents rated different elements of services within satisfaction surveys they reported positively on some elements of services despite being dissatisfied with

information provision (Matziou et al, 2011; Solheim and Garratt, 2013). However, overall satisfaction ratings were closely associated with parents' evaluations of information provision (Matziou et al, 2011; Solheim and Garratt, 2013). In studies where parents were dissatisfied with communications or inter-actions with professionals this was attributed to a lack of training in communication skills (Avis and Reardon, 2008) or time pressures, availability of health professionals and work environments (Matziou et al, 2011).

Interactions with staff were identified as an important factor in parents' experiences of their child's hospitalisation and were necessary to enable parents to work with health professionals in their child's care. Overall satisfaction with hospital care was found to have a statistical association with parents' satisfaction with staff and information provision specifically regarding medications (Solheim and Garratt, 2013). Parents who felt they did not have sufficient personal contact and opportunity for interaction with professionals felt generally dissatisfied with care (Matziou et al, 2011) even when interactions with the staff had been positive.

In a study undertaken in a surgical area (Simons, 2002 - see earlier discussion in, parents: satisfaction with care section), interactions were noted to be generally nurse-initiated and parents reported feeling uneasy about questioning practices. The researchers felt that the parent-nurse relationships were 'quite imbalanced' and nurses were noted as 'keeping their distance' to some extent (Simons, 2002, p.1447). Although these interesting aspects of nurse-parent interactions were commented upon in the findings they were not further explored with the nurses or parents to enable a full picture to be built up of the

encounters from both perspectives. The positioning of nurses in relation to parents has been commented in another study (Coyne, 2007, p.3152) where nurses described allowing parents to 'stand back' initially in relation to their child's care. The nurses then took a 'step back' themselves in the belief that this allowed parents to take on the care thus fulfilling their parenting needs. However, in the absence of a discussion between parents and nurses the different positions adopted by nurses led parents to make assumptions about what nurses' behaviour meant and what was therefore expected of themselves (Simons, 2002; Coyne, 2007). These findings may highlight sources of potential tensions within nurse-parent relationships in relation to the dissonance between nurses' behaviours and parents' interpretations of these behaviours that warrant deeper exploration.

In Espezel and Canam's study (2003) parental sensitivity to nurses' behaviours was also noted: when the child was acutely ill the nurses' manner was seen as neutral, care was more task orientated with limited conversations with parents other than short, factual and technology dominated conversations. However, as the child's condition improved parents commented that nurses talked more about the positive signs of the child's status and also about their previous experience with other children in similar circumstances (Espezel and Canam, 2003). The sample of parents in this study were all parents of children with complex care needs who were experienced in being in hospital with their child. It is, therefore, not possible to determine whether such close scrutiny of the nurses' patterns of inter-actions by the parents or the parents' interpretations of the nurses' behaviours would be the same for parents new to this situation.

In this review, experienced parents of children with on-going health problems reported that a central aspect to effective interactions between parents and nurses was establishing a rapport that ultimately enabled them to share their child's care (Espezel and Canam, 2003). Developing such a rapport from the parents' perspective was important as they felt that they could then work together effectively with nurses to care for their child (Espezel and Canam, 2003). Parents valued continuity of the nurses caring for their child and felt more comfortable with staff who knew their child. The more contact parents had with the same staff the more they were able to build up a rapport with them and thus their confidence in them. Parents acknowledged that development of these relationships required an investment of time by both parties as information was exchanged between parents and nurses. Establishment of rapport, parents felt, was influenced by nurses' knowledge of the child, parents' knowledge of the nurse, and their ability to find common connections between them (Espezel and Canam, 2003). It was proposed that parents encountered difficulties in establishing rapport when there were high rates of staff turnover, where it was not clear who was looking after their child or if nurse-parent interactions were brief and merely focussed on physical care of the child (Espezel and Canam, 2003). These findings may be interpreted as there being a strong parental need to develop a relationship with the nurses requiring time, effective communications and meaningful interactions to enable its establishment. Findings from Coyne's study (2007) appear to bear out these interpretations as it was noted that relationships became increasingly tense and challenging where nurses avoided interactions with parents who were seen as demanding or difficult, preferring to spend more time with those perceived as 'nice families'. Similarly, development of a trusting relationship

between parents and nurses was thought to be undermined where parents felt they were just left to recognise and respond to their child's needs without any acknowledgement of their own needs for emotional support and information (Avis and Reardon, 2008). It appears that within these studies (Espezel and Canam, 2003; Coyne, 2007 and Avis and Reardon, 2008) there is a common theme that emerges of the parental need for positive interactions with nurses, demonstrating sensitivity to the parents' situation and allowing them to develop effective relationships to facilitate their child's care. These studies contribute important information with regard to parent-nurse interactions although the limitations of the individual samples and the focus of the studies mean that unanswered questions still remain. Espezel and Canam (2003) acknowledge that whilst their study described parental experiences of such interactions their findings did not extend to exploring parental perception of the outcomes of the interactions. Similarly, Coyne's study (2007) provides some interesting perspectives from nurses' about managing parental behaviour within a ward setting, however, it raises some questions that are worthy of future examination to enable a fuller understanding of the complexities of nurse-parent interactions within hospitals.

Similarly, in Stratton's grounded theory study (2004) of parents' experiences of their child's hospital care, it was proposed that parents relied on their relationship with care providers for support to enable them to cope with their child's illness. It was suggested that parents wanted an interactive relationship with staff that not only communicated information relating to their child's care but that also displayed compassion, understanding and sensitivity to parent and child's needs. The parents' ability to develop such relationships with staff

influenced how well they felt that their needs and their child's needs were met. Four categories were identified within the data: facing boundaries; attempting to understand; coping with uncertainties and seeking reassurances from care givers. These categories described the way that parents initially felt helpless and played a passive role in their child's care, accepting professional care and its authority and sought comfort from staff as they struggled with their fears about their child's illness. Parents felt a need to always be with their child to make sure that nothing went wrong and particularly valued care-givers who demonstrated concern; were supportive and were attentive to detail. All parents wanted hospital staff to interact in a meaningful way with them and their child in the process of providing care. The hospital environment was thought to place limits on normal parental roles therefore parents depended on staff inter-action to provide them with guidance. Findings from this study may be limited in terms of transferability as the majority of children had been cared for in local hospitals not designated as children's hospitals and all parents were Caucasian. In addition, despite being a grounded theory study, convenience rather than theoretical sampling was used to recruit a relatively small sample of parents and this may have impacted on the researcher's ability to seek out key informants to further explore emergent themes. However, there were a number of recognisable strengths within the sample in that it reflected diversity, in terms of children's ages and their illness experiences and both mothers' and fathers' perspectives. While taking into consideration potential limitations previously outlined, conclusions from this study introduces the interesting notion of parents using the parent-nurse relationship within their evaluation of whether both child and parental needs are being met.

Discussion of the theme of communication and interactions from a parental perspective has provided some key messages indicating the centrality of this issue to parental evaluations of quality of care. Issues with miscommunication and misinterpretations have been identified and highlight areas for quality improvement. The next theme to be considered relates to emotions and encompasses aspects of experiences from the studies that related to parental feelings as they stayed with their children through their hospitalisation.

Parents: Emotions

Children's hospitalisation impacts on parents emotionally but also causes various disruptions to family routines (Sartain et al, 2001; Coyne and Cowley, 2007; Tong et al, 2010). In addition, parents experience considerable stress and anxiety when their child is admitted to hospital and borderline clinical levels of anxiety continue for some parents even three months after discharge (Wray et al, 2011). Higher levels of anxiety amongst parents of hospitalised children are associated with maladaptive coping strategies, higher levels of illness, uncertainty and previous hospital admissions (Wray et al, 2011). Parents of children with special needs often have frequent hospital admissions and these parents report significantly higher levels of perceived stress than those of other parents prior to admission (Phua et al, 2005). Similarly, parents of children with complex care needs reported heightened emotions during hospitalisation and explained that such admissions often evoked distressing memories associated with their child's initial diagnosis and continuing health problems (Avis and Reardon, 2008). Parents saw each admission as part of their developing story

and looked back at the impact of their experiences as leaving "scars" for the future (Avis and Reardon, 2008, p.12).

Heightened emotions within the hospital situation were experienced by parents ranging from varying levels of fear, anxiety and stress to elation and relief (Matziou et al, 2011; Peeler et al, 2015). In Matziou et al's (2011) survey, the majority of parents (*n*-166, 80.58%) reported either feeling a high level of anxiety or a level of anxiety, to a certain degree, when their child was hospitalised. It was also noted that parents who reported they were not anxious, rated significantly higher satisfaction with their participation in care and child's medical treatment whilst they also rated higher overall quality scores compared to most anxious parents (Matziou et al, 2011). This link between parental anxiety levels and satisfaction scores is interesting, although it is not possible from the data to detect whether less anxious parents perceived care quality to be better than more anxious parents or whether high quality care provision positively impacts on parents' anxiety levels.

Uncertainty, lack of information, lack of clarity of roles and responsibilities, feelings of inadequacy, isolation and fear of the unknown were all identified as potential causes of parental anxiety and stress when children were hospitalised (Coyne and Cowley, 2007; Avis and Reardon, 2008; Peeler et al, 2015). In a recent phenomenological study (Peeler et al, 2015) mothers described their child's emergency admission with a severe respiratory infection as a terrifying, stressful experience and a major event for them and whilst the nurses realised the mothers were anxious, they did not seem to fully appreciate the extent of their fears. In this study, mothers (*n*-12) and nurses (*n*-12) who had cared for

their child were purposively selected to take part in semi-structured interviews. It was reported that data saturation was not achieved with an initial sample of participants ($n=12$) so further participants were subsequently recruited and interviewed. These adjustments can be viewed as both strengths and weaknesses of the study. Additional steps taken to reach data saturation provides some assurance that analysis did not ended prematurely. However, recruitment of the second sample several months later meant that for some mothers they were reflecting on a recent experience and for others it was some time earlier. Personal recall and possible changes in perspective with time may have influenced findings. Although both parents were invited to take part in the study, only mothers participated which limits the perspective explored to mothers' rather than parents'. However, these findings provide important contributions to knowledge in this area, in relation to critical differences in mothers' and nurses' perspectives when an infant is hospitalised. A further strength of the study is that the nurses interviewed had looked after the infants and their mothers during their hospitalisation thus providing two perspectives on the same events. Mothers recounted that, at the time of the experience, they were extremely fearful that their child might die and this was compounded by their inability to comfort their child (due to oxygen therapy via a head box), lack of control and understanding of the situation which left them feeling isolated, inadequate and poorly equipped to deal with the experience. Nurses' accounts suggested their main focus was about the infant's safety and the technical care they were delivering (Peeler et al, 2015). Similar to other studies (Stratton, 2004; Tong et al, 2010) this study found that information was viewed positively by parents as a way of alleviating their anxieties; helping them understand the situation; build rapport and a trusting relationship with health professionals.

There was considerable variation in the way that parents perceived nurses. Some parents said they trusted and respected nurses and held them in high regard for their work whilst others felt nurses lacked a caring approach (Avis and Reardon, 2008) or lacked sympathy and appreciation of their fears (Peeler et al, 2015). Parents also said that they wanted staff to interact with them and their children when providing care and not just perform the technical tasks required (Stratton, 2004; Espezel and Canam, 2003). Parents recognised that nurses were busy but reported that individual nurses differed in their approach, with some ensuring they made time for families despite being busy (Avis and Reardon, 2008). Parents identified desirable characteristics of nurses to include - showing concern, being supportive, attending to detail (Espezel and Canam, 2003) and being caring and trustworthy (Avis and Reardon, 2008).

Parents described the disruption to normality and their family life when their child was hospitalised (Sartain et al, 2001; Coyne and Crowley, 2007; Tong et al, 2010) including having to take time off work, alter child care and travel arrangements (Sartain et al, 2001; Peeler et al, 2015). Similar disruptions are noted by children and are reported in the children's perspectives section of this review. The additional costs of hospitalisation for parents were also acknowledged in several studies (Sartain et al, 2001; Coyne and Cowley, 2007; Hughes, 2007). Frequent and lengthy hospital stays left parents feeling disconnected from the outside world (Tong et al, 2010) whilst some fathers identified difficulties balancing work and care responsibilities acknowledging the emotional impact of their child's illness on their work (Higham and Davies, 2012). Other children in the family were equally affected as their usual activities and routines were changed and different family members or friends cared for

them (Peeler et al, 2015). In a study which compared families' experiences of hospital and home care for acute illness (Sartain et al, 2001), 55% of parents whose child was hospitalised felt that this had caused much alteration to their lives e.g. taking time off work, changing child care and travel arrangements. Whereas 95% of the parents of children in the home care group reported minimal disruption caused by caring for their child at home. 90% of all parents in the study would prefer home care, in the future, rather than hospital admission for their child provided the illness was neither serious nor life threatening and care needs could be met at home with appropriate professional support. Parents reported that this was their preference because home was more comfortable, there was more freedom, more time with nursing staff on a one-to-one basis, continuity of normal family life, less financial cost and a perception that children recover better at home. However, researchers suggested that parents concern for their children appeared to over-ride any considerations of social and financial costs when determining the best place of care for their ill child.

Findings discussed within this theme have highlighted some important issues relating to the disruptive nature of hospitalisation for families as well as the extent of the fear and anxiety felt by parents during these experiences. Variance between parents' and nurses' perspectives has emerged within the discussions and this issue continues to emerge within the following section which focuses upon parents' involvement in care.

Parents: Involvement in care

Parental involvement in care is consistent with the fundamental philosophy of children's nursing in which family-centred care and parental partnership working are considered to be central to care delivery. The studies reviewed here found that parents wanted to be with their child when they were hospitalised (Higham and Davies, 2012; Coyne, 2015; Peeler et al, 2015) and many parents wanted to be involved in their child's care (Sartain et al, 2001; Espezel and Canam, 2003; Stratton, 2004; Hughes, 2007; Coyne, 2015; Peeler et al, 2015). However, the extent to which parents wished or expected to be involved in care varied and the prime reason parents gave for being with their child in hospital was not necessarily to deliver care but to provide a sense of normality through their presence; emotional reassurance and support; distraction from fears and anxieties all of which they saw as helpful in their child's recovery (Sartain et al, 2001; Coyne and Cowley, 2007; Coyne, 2015). Parents reported not knowing what was expected of them in hospital and they felt there was a lack of communication, explanation and negotiation with them about their role (Hughes, 2007; Coyne and Cowley, 2007; Higham and Davies, 2012; Coyne, 2015). Parents' involvement was usually assumed rather than negotiated (Hughes, 2007; Avis and Reardon, 2008; Higham and Davies, 2012; Coyne, 2015) and some parents felt obligated to stay and look after their child as this seemed to be expected of them, the nurses were busy or they worried that their child may not receive the most appropriate care if they did not provide the care themselves (Hughes, 2007; Coyne and Cowley, 2007; Avis and Reardon, 2008; Coyne, 2015; Peeler et al, 2015).

In addition, mothers reported feeling responsible for their child's care when there was limited communication from nurses of their expected role (Coyne and Cowley, 2007) although some worried about overstepping boundaries when providing care (Coyne, 2015). Where parents perceived that information was not being effectively shared between nurses and doctors they felt they had to act as the channel for communicating information (Avis and Reardon, 2008) and parents viewed this as an indicator of poor team work and poor quality care (Avis and Reardon, 2008; Byczkowski et al, 2013). Positive relationships with nurses were most likely to develop when parents felt nurses knew and showed interest in their child (Espezel and Canam, 2003; Avis and Reardon, 2008) and when they acted as a mediator between them and the doctors (Espezel and Canam, 2003).

In a recent study focussing on the father's role during their child's hospitalisation (Higham and Davies, 2012) both parents and nurses expressed their expectations that a parent would be resident throughout the admission. Despite fathers being observed providing a wide range of their child's care, fathers, mothers and nurses still felt that mothers were main or natural carers for children. Fathers were also found to take a secondary role in decision making about their child. Protecting their child and partner was viewed by fathers as an important aspect of their role and they were observed carrying out various protective behaviours by researchers. Protective behaviours included: physical presence and 'being there', 'being strong' and acting as a an advocate for their child and partner (Higham and Davies, 2012). There are some limitations to the study's findings as participants' views may not necessarily reflect views of those fathers who declined to be interviewed. The sample did not include younger fathers despite efforts to recruit across the age range and this may

further limit the findings. The study's ethnographic nature required observation on the wards and this may have caused fathers to act differently knowing they were being observed. Researchers acknowledged this issue but suggest that the impact of this may not be as evident within a ward situation as in a more private setting. Although researchers stated that fathers were keen to share their experiences with them their responses may have been affected by the use of female researchers. Despite these potential limitations this study provides some important insights into the fathers' role and given the limited attention that has been paid to this aspect of a child's hospital care to date, this work provides an important contribution to the knowledge base.

Relationships between nurses and parents have been reported as neither collaborative in nature at times (Espezel and Canam, 2003) nor as partnerships (Coyne and Cowley, 2007) due to the power and control that was seen as being exerted by nurses. Despite these perceived difficulties some parents of children with additional needs continued to report satisfaction with their interactions with nurses and described developing a rapport with some nurses with whom they then felt they could share their child's care (Espezel and Canam, 2003). In a descriptive survey of attitudes of parents and nurses to the implementation of a partnership approach to care within an in-patient setting both parents and nurses suggested that they considered this an appropriate model of care (Hughes, 2007). Despite discrepancies in how parents and nurses viewed their respective roles and greater self-evaluation ratings by the nurses than the parents ratings of nurses in relation to nurses' teaching skills, generally parents were satisfied with care provision. Differences reported between nurses' and parents' perceptions of nurses' teaching further demonstrates the need to capture feedback from those receiving a service as it seems the providers, in

this case, were unaware of how parents' views differed from their own. Findings of this study are limited as they provide only descriptive information of parents' and nurses' views specific to their own setting and are unable to offer any further in-depth information to understand why the participants responded in the way that they did. In addition, the sample excluded non-English speaking parents which may have impacted on the results.

Findings from the reviewed studies relating to the theme of involvement in care have again demonstrated some differences between parents' and nurses' perceptions. The potential for these differences to become problematic within parent - professional relationships has been identified and will be re-visited later in this chapter when studies relating to health professionals' perspectives are reviewed. However, discrepancies between different outlooks continue to feature within the next section of this review as the theme of parents' queries and concerns sometimes reflect these variations in views.

Parents: queries and concerns

The theme of queries and concerns emerges from several studies which have highlighted aspects of parents' experiences that may be problematic. Whilst parents themselves may not have identified these areas as being problematic or a source of dissatisfaction their comments do appear to indicate areas of concern.

Within the studies reviewed there was a recognition that parents' previous experiences and their levels of anxiety and fear may impact on the way that they acted when their child was hospitalised. This was particularly noticeable in studies exploring views of parents of children with special or complex needs. In Avis and Reardon's study (2008) one mother described the repeated experiences of being in hospital with her child as her 'hospital career' (p. 12). The previous experiences, initial impact of the diagnosis of a long term condition and on-going daily additional stress in these parents lives generally increased their anxiety levels and may well impact on the way that these parents enter each subsequent hospital admission and their interactions with staff. In considering these findings it should be noted that the sample was relatively small and consisted of parents of children with additional needs recruited from the same respite care setting which may have limited diversity within the views obtained. However, a strength of the study was the way that researchers carried out some initial data analysis and identified the need to purposively recruit parents from black and ethnic minority backgrounds and parents with more than one child.

Parents' previous health care encounters have been identified by some nurses as impacting on their expectations and perceptions during subsequent hospital admissions and this could cause difficulties (Coyne, 2007). Despite recognising that potentially problematic situations may arise when parents enter the ward with increased anxiety levels and previous poor experiences the nurses' strategies for managing these relationships appears to be one of controlling parental behaviour (Coyne, 2007). It seems that these strategies sometimes served to increase parental dissatisfaction resulting in challenging interactions. Methods used by nurses to control the behaviour of parents on the ward were

described as inclusionary and exclusionary tactics where parents were persuaded or coerced into behaving in the desired manner whilst on the ward i.e. staying with their child, being involved in their care and behaving 'properly' (p.3150). Parents who conformed to nurses' perceptions of being a good parent were rewarded by being labelled as popular and nurses spent more time with them whilst parents seen as deviant and non-compliant were punished by nurses avoiding them, removing support and labelling them as problematic. Such controlling approaches often resulted in continuing difficulties within nurse-parent interactions. In considering these findings the relatively small sample size and limited range of nursing grades within the participants should be recognised. The number of years of experience of the nurses is not identified although this may have had a bearing on nurses' attitudes and responses. However, the varied age range of participants (24-42 years) suggests that there may have been some relatively newly qualified nurses and some more experienced nurses within the sample. A strength of the sample was that nurses were recruited from two different units thus increasing likelihood of more diversity within the views gathered.

Whilst nurses may perceive difficulties with parents' behaviours prompting them to adopt various strategies to manage this situation, it is not clear if parents may equally find the nurses' behaviours to be difficult. Some parents, for example, have reported a reluctance to question nurses' practice (Simons, 2002) and have indicated they have had worries about raising their queries or concerns with staff in case this negatively affected their relationship with them (Tong et al, 2010; Coyne, 2015). Some parents felt there was deterioration in relationships with staff when they raised concern about lack of support for themselves

(Coyne, 2015). There was a perception that staff had little tolerance for parents' queries and there was, therefore, a risk of being seen as being difficult (Tong et al, 2010). In this study the sample consisted of parents of children with chronic kidney disease; recruitment of parents from two centres alongside purposive sampling to ensure participants had experiences at all stages of CKD strengthened the study's findings. However, a limitation was the lack of any non-English speaking parents restricting to some extent transferability of the findings. Findings report responses as being from 'parents' so it is not possible to ascertain whether mothers and fathers in this study differed in their attitudes to health professionals, and this would have been interesting to examine particularly in relation to this notion of being viewed as being difficult. It is interesting to note that similar concerns were acknowledged, but did not deter fathers in an ethnographic study of fathers' roles in children's hospital care (Higham and Davies, 2012). Fathers' reported feeling it was their responsibility to raise concerns with staff about perceived inadequacies in care for their child or partner. Researchers confirmed through their observational data that nurses, as parents suspected, interpreted these requests as being from 'demanding' parents (Higham and Davies, 2012). As previously discussed, such labelling of parents by nurses was also seen in Coyne's study (2007) where 'nice families' were identified and treated in a different way to those that were seen as troublesome, non-compliant and disruptive to the order of the smooth running of the ward. Coyne (2007) concluded that nurses needed to be supported to cope more effectively with parents, be more cognisant of individual circumstances rather than depending on subjective judgements and assumptions about parental participation thus minimising potential for adversarial nurse-parent interactions. Recommendations proposed that nurses

needed to explore with parents their expectations to reduce disagreements and appreciate the differences in perspectives of professionals and parents.

Discussion of some elements of this theme of queries and concerns continues later in the health professionals' perspective section of this review e.g. control of parental behaviours within wards. However, the message that emerges again from this section is that differences often exist between parental and professional viewpoints and this can be a potential source of difficulty in relations within wards. This section has concluded the discussion of parental perspectives and the next section will now consider reviewed research studies relating to children's perspectives of the quality of their care experiences.

Children's perspectives

Although parental perspectives on their child's hospitalisation is the focus of this thesis it is acknowledged that children's views on hospital care offer a different but equally important perspective. Children have the right to be heard in all matters which concern them (United Nations, 1989) and it is expected that these rights underpin the legal frameworks within each country that has signed the Convention of the Rights of the Child (United Nations, 1989). In the UK there has been an increasing recognition of the need to involve children in health service developments and there are innovative examples of children's views being incorporated into the service design of many health care facilities. Hospital design, service development and healthcare professional education programmes have all benefitted through young service user input over recent years.

In this review of the literature relating to children's perspectives of hospital care five main themes emerged:- communication, emotions, involvement, environment, health professionals. Whilst some of these themes identified mirror those previously discussed in the parental perspectives section of the review, for example, communication, emotions and involvement, others are specific to children's studies, that is, environment and health professionals. Although these themes may have emerged as important to children anyway, it should be noted that a number of studies specifically focused on environment and health professionals. The first theme to be discussed in this section of the review focuses upon children's perspectives on communication.

Children: Communication

Communication was a predominant theme within the literature and was identified as an area that caused concern for children. The over-arching communication issues that arose in studies related to the child and family being given sufficient and appropriate information about the child's clinical condition, interventions and appropriate involvement of children in discussions about decisions. Children described a 'good nurse' as one that communicated well with them, praised their bravery and were honest with them (Brady, 2009). They also identified that it was very important for them to know what would happen to them and to be kept informed (Pelander and Leino-Kilpi, 2004). A study was undertaken with children to explore their views of hospital experiences with the aim of informing future development of more child-centred services (Carney et al, 2003). In relation to communication, findings suggested that children liked it when staff were friendly, helpful, reassuring and provided explanations but

disliked staff who they perceived as controlling or who did not give appropriate explanations. They preferred to have interactions with staff who were familiar to them and also highlighted that health professionals sometimes used words that were incomprehensible to them. The notion of familiarity links with developing relationships with staff and this has previously been identified as important for children in hospital and whilst this may be something also valued by parents it would be useful to explore from both perspectives where this ranks in importance in terms of their experiences.

A second aim within this study was to evaluate the most effective way of gathering children's views by using four different questionnaires: verbal structured - children were asked five questions about being in hospital; verbal unstructured - children were invited to write a poem or story about their hospitalisation; visual structured - children shown five drawings of different aspects of a hospital experience and completed a large thought/speech bubble; visual unstructured - children asked to draw a picture about being in hospital. However, evaluation of the different types of questionnaires used appear to be evaluated only in terms of the amount of data that was obtained from the tool; the more structured questionnaire yielded largest amounts of data. However, it could be argued that this may be the most biased information as it could be heavily guided by structured questions whereas unstructured approaches may capture a more genuine view of children's priorities. Greater analysis of the type of data offered by different questionnaires could have provided a more robust evaluation of methods. Further enhancement to the evaluation could have been achieved if researchers had recorded observations of children's reactions to questionnaires; children's levels of comfort or enjoyment at participating could have been measured through self-report using a child-

friendly likert scale with parents/professional ratings as a comparison. However, it is possible that some children may be less comfortable with unstructured approaches as they may feel vulnerable expressing their own ideas and feel unsure, believing there is a correct answer to the task set.

Children reported a range of experiences in information provision in hospitals (Lambert et al, 2012) which had both positive and negative impact on them. When children perceived information provided was given too late or was generic, inadequate or superficial they felt worried and unprepared (Coyne and Kirwan, 2012; Lambert et al, 2012). They were also upset if they felt excluded from conversations about information and decision-making through professionals directing information to their parents or using language that was meaningless to them (Coyne, 2006b). Children reported wanting to understand their own care and be included in discussions but noted that doctors and nurses often used jargon, long and complex sentences that made it difficult for them to participate (Coyne and Kirwan, 2012). Children described gathering information about their hospitalisation indirectly, for example, reading leaflets sent to their parents which were usually generic and aimed at an adult audience. Children also reported that doctors did not usually speak directly to them but spoke to their parents when providing information (Smith and Callery, 2005). Similar experiences have been reported in other studies where children felt they merely 'eavesdropped' on exchanges between staff and their parents without really understanding the conversations (Lambert et al, 2012). Absence of information sometimes caused children to use their imagination to fill in gaps in their knowledge (Lambert et al, 2012) which could be much more frightening than reality and other children admitted that whenever staff wanted to speak in

private to their parents they assumed that this was to give them bad news (Coyne and Kirwan, 2012). Overall, children reported that they felt disappointed and upset when they were not listened to by staff and did not have their questions answered (Coyne and Kirwan, 2012).

Some children identified a hierarchy amongst the staff with medical staff more senior than nurses and students as most junior (Lambert et al, 2012). According to children the more senior the member of staff the less likely they were to make conversation with the children, provide information or provide information that could be understood (Lambert et al, 2012). Similarly, Coyne (2006b) found that children thought some doctors did not explain information well often using technical terms or just talking to their parents. There was still an expectation amongst children that medical staff should provide information to them directly even if they could not understand it. This point is interesting as there is an acknowledgement in adult nursing that where patients are not able to understand information, for example, where they have a learning disability or dementia, health professionals are still expected to be socially respectful by including them in communications rather than talking over them. This perhaps highlights differences in mind-sets when communicating with children compared with vulnerable adults; professionals working with children may need to re-appraise their approaches to ensure that they are acting in ways that uphold the child's rights to information and are respectful of them.

Interpretation of information so that children can understand it was identified as essential for many children. Both nurses and parents played important roles in simplifying information for children with some children preferring their parents to

explain things to them (Lambert et al, 2012). Children varied in their informational needs with some viewed as 'active navigators' searching for knowledge by questioning professionals or parents, interacting with other children and observing their surroundings (Lambert et al, 2012, p.346). Others did not want to be given information for various reasons, for example, feeling unwell, fear of what they would be told or not feeling ready to cope with information. These differing needs for information presents challenges for staff in how best to assess and meet individual's needs. When children were asked about their wishes in hospital they identified that they would like staff to answer all their questions and not be annoyed if they asked 'silly' questions and they wanted to be kept updated. They recommended that health care professionals should make a better effort to listen and to take account of children's views (Coyne and Kirwan, 2012).

The findings discussed in this section relating to communication demonstrate that children have some clear ideas about how they would prefer to be communicated with in hospital. Despite progress in recognition of children's rights over the years, findings discussed here have highlighted areas where children receive limited information directly and their voice was not always heard. Children have provided some insightful perspectives from their observations and experiences in hospital highlighting areas for future improvements. The next section of this review considers the theme of emotions within the studies focussed on children's perspectives. Emotions and feelings featured as an important issue within parents' perspectives of their hospital experiences and similarly this theme is a dominant one for children.

Children: Emotions

Children's views of hospitals vary considerably with some children seeing them as 'horrible', 'depressing places' (Coyne and Kirwan, 2012 p.295) or scary places where there are ill people (Carney et al, 2003), whilst others describe them as places where people recover from illness, rest, receive extra care and may feel special (Carney et al, 2003; Coyne and Kirwan, 2012). It is generally acknowledged that children's worries about going into hospital are often rooted in their fear of the unknown (Coyne, 2006, Fletcher et al, 2011) and are associated with preconceptions developed from experiences at school, with friends and watching television (Smith and Callery, 2005; Coyne, 2006a). However, children who have actual experience of being in hospital have reported feelings of anxiety and worry but also describe feeling a sense of relief and happiness when hospitalised (Carney et al, 2003). These apparently contradictory feelings are perhaps explained by the concept that children's fears and negative perceptions of hospitals are labile and can be overcome through positive interactions with staff and parental presence and support (Carney et al, 2003; Pelander and Leino-Kilpi, 2010). Fletcher et al (2011) further supported this notion by suggesting that while children's initial fears about hospital admission may centre on fear of the unknown, once admitted and their fears dispelled, their worries moved on to their next concerns - the care environment and their own personal and social needs.

The notion of children experiencing seemingly opposing emotions about their experiences of hospital continues to recur as a sub-theme within the studies. In a constructivist grounded theory study, Ford (2011) explored children's

experiences of hospital admission for surgery and found they expressed a whole range of quite different feelings about their experiences including being fearful and being in pain but also enjoying themselves and having fun. The sample of children ($n=10$) were aged between 6 and 12 years of age who had planned or unplanned surgery within an Australian hospital. Limitations within the research include lack of reported details about participants, for example ethnicity and gender, recruitment and data analysis. However, the child-friendly approaches used to gather data are commendable with a combination of interviews; field observations; children's drawings and stories using 'draw and write' techniques (Pridmore and Bendelow, 1995) enabling collection of rich data over several time points. Findings suggested that children's anxieties and lack of control in their experiences were alleviated by staff and parental interventions which empowered the children, promoting their own coping and sense of well-being. Ford (2011) proposed that children require additional social and emotional support from parents, families and staff to help them to cope in hospital and found that such support was highly valued by children as it gave them a feeling of being cared for and enabled them to successfully deal with the stress of hospitalisation. Similarly, Coyne, (2015) found that children were reassured and relied on parental presence and involvement in their care.

Hospitalisation for many children brought with it a number of changes to their lives which evoked for them some strong emotional responses. Children disliked the disruption hospitalisation caused to their normal lives, activities and social contacts (Coyne, 2006; Pelander and Leino-Kilpi, 2010) and the lack of independence and control they felt in hospital (Coyne, 2006a). Separation from family, friends, pets and familiar home life was difficult for children (Sartain et al 2000, Carney et al 2003, Coyne, 2006a; Pelander and Leino-Kilpi, 2010;

Lambert et al, 2013) whilst in hospital but they felt happy when their parents stayed with them and glad when they were able to return home (Carney et al, 2003).

Whilst for some children the disruptions and upset caused by hospitalisation was a one off event, for other children with chronic illness such experiences were a regular event. Sartain et al (2000) used a grounded theory approach to explore children's' (age 8-14 years), parents' and professionals' experience of chronic illness and used both semi-structured interviews with draw and write/tell techniques to successfully elicit the views of the children. Although the study's limitations include the relatively small sample size (*n=7 families and professional carers*) and lack of representation of different ethnic groups within the sample, the strengths lie in the effective way in which child-friendly approaches appear to have enabled children to open up to researchers providing some insightful perspectives to be obtained. Findings described children's views of the worst things about being in hospital as:- being woken up in the night, taking medicine, food, school and not being at home. The children also described feelings of boredom, insecurity and feeling forgotten about and they often felt unhappy because their illness impacted on their lives and made them feel different to other children. Normality was missed and they disliked the general disruption to their usual routines at home, their peers and school lives. Similar findings were noted by Coyne (2006a) in relation to children's dislike of the disruption caused by hospitalisation. However, some children who were frequent attenders enjoyed being with the other "regulars", adjusted to hospital life and liked knowing that there was always someone to play with, compared to being at home (Sartain et al, 2000).

Children have also deemed the worst aspects of hospitalisation to be those associated with the symptoms of their illnesses; separation from parents, family and friends, home and school; being in an environment where physical care, treatment and procedures occurred; food/eating restrictions and waiting for procedures (Pelander and Leino-Kilpi, 2010). Children have also reported issues affecting them sleeping on the wards such as babies and children crying, nurses conversations, telephones ringing, in addition to problems with ventilation and bright lights (Coyne, 2006a). Lack of activities and privacy were listed amongst other aspects of hospitalisation disliked by children (Pelander and Leino-Kilpi, 2010).

Some children listed the nicest things about being in hospital as:- the playroom, the school, the food, the nurses, having visitors and making friends (Sartain et al 2001). It was suggested that some children attempted to minimise the disruptions caused by hospitalisation and regain some personal control by personalising their own bed space and bringing in their own games so that hospital looked and felt more like home (Sartain et al, 2000; Coyne 2006a; Coyne and Kirwan, 2012). Children have commented that lack of information and preparation caused them anxiety and suggested pre-admission visits as a way of combating these feelings (Coyne and Kirwan, 2012). Maintenance of critical relationships with parents and families, positive inter-actions with healthcare professionals and participation in enjoyable activities were all aspects of hospital experiences viewed as positive aspects of hospital experiences (Pelander and Leino-Kilpi, 2010; Ford 2011).

Findings discussed in this section have, as one might have expected, demonstrated the central nature of a child's emotions within their hospital experiences. However, whilst fear and anxieties were expressed within the findings the way that children's worries could generally be overcome through positive experiences was evident within the theme. Within the next section the theme of involvement in care will be discussed from children's perspectives. Although involvement in care emerges as an issue for both parents and children there are some key differences between these perspectives. Areas for discussion within parental involvement in care related to roles and relationship delineation, mainly between nurses and parents but for children the issues relate mainly to inclusion in decision-making.

Children: Involvement

During hospital experiences children seem to encounter a range of infringements to their personal independence compared to the way they normally live their lives at home. In a grounded theory study of children's hospital experiences (Coyne, 2006a) children's descriptions demonstrated how they lost control over basic decisions in their daily lives, for example, the time they awoke or slept, ate, drank or used ward facilities. Areas of their lives previously determined by themselves required permissions, for example, getting up and dressed, using the bathroom and leaving the ward. This study's sample (*n*=11) included children and young people (7-14 years). Whilst the relatively small sample size is a limiting factor in this study, participants were drawn from four paediatric units in England and included children with and without previous hospital experiences which may have increased diversity of views. Differences

in views may be considerable between a seven year old and a teenager particularly in relation to independence and control within their hospital experiences and further research to fully explore this area would be beneficial. Children's reports of curtailment of their independence whilst in hospital alongside a lack of any control or choice about even their own bed area potentially demonstrated to them the limited power they held within the ward (Coyne, 2006a). These were not the only areas in which children had little control and choice as many decisions and discussions about their condition and care appeared to occur without their full involvement.

The rights of children to be involved in decisions affecting them is upheld within the United Nations Convention on the Rights of the Child (UNCRC, 1989), however, the extent to which this is enacted routinely by health professionals within hospital care seems variable. A study carried out in Sweden (Hallström and Elander, 2004) used non-participant observation to gather data to determine the type of decisions taken during a child's hospitalisation and how these decisions were made. Findings showed that decisions were mainly clinical in nature and in 218 observed situations professionals alone made decisions in 106 cases; parents in 10 cases; the child in 3 cases and mutual decision making with those affected by the decision occurred in 99 cases. These findings suggest that it is health professionals that acted as main decision makers with parents and children rarely making decisions themselves. It could be argued that this situation may reflect the clinical nature of the decisions and the need for health professionals to lead in such decisions. However, there were 83 cases where parents or children disagreed with decisions but decisions were not changed by professionals, which suggests an

unequal balance of power in decision making within the professional, parent, child triad.

One might anticipate that as children's rights have become more prominent in the last decade that children's level of involvement in decisions about hospital care may have improved. However, it seems that children's inclusion in discussions of matters concerning their care and treatment continues to be variable. In a qualitative study (Coyne and Gallagher, 2011), children aged between seven and eighteen years of age ($n=55$) took part in focus groups and individual interviews to explore their experiences of participating in communication and decision-making. The findings suggested that children wanted to be included in communications and decision-making about their care but they often felt they were treated as less important in these exchanges by both health professionals and their parents. Children varied in the extent they wanted to be involved in decision-making with some just wanting to make basic decisions and leave more important decisions to professionals and parents whilst others wanted to share decision-making. It was proposed that it was the professionals' and parents' behaviours that usually limited the children's input although this was only based on analysis of the children's reports. In future research collection of observational data to triangulate such interview data may provide a more robust account of the exchanges between professionals, parents and children. Coyne and Gallagher (2011) concluded their study by suggesting that a single approach to children's involvement in decision making in practice was not feasible given the variation in the extent to which different children wished to be included.

The findings discussed within the theme of involvement in care from the children's perspectives have re-iterated areas for improvement within children's hospital care. The improvements identified relate to the need to respect the children's rights to be included in decisions about themselves. There are also some important messages from the research about the extent to which children's independence is sometimes compromised within the hospital system. The next section of this review focuses upon the children's views of the environment both from experience and in planning for the future.

Children: Environment

The studies from which this theme emerged either canvassed children's opinions about their previous hospital experiences generally or involved children in specifically designing ideal hospital environments for the future. The studies that generally explored children's experiences of hospital found that the environment was very important to children and was frequently commented on within data gathering. This theme was not one that appeared within the parental perspectives section of this review and this suggests that the environment may have far more impact on children than on their parents.

Children described hospitals as being an unfamiliar environment and disliked the noisiness of the ward; the bright lights at night; the hot environment; inadequate play facilities; lack of privacy and the food (Sartain et al, 2000; Coyne, 2006a; Pelander and Leino-Kilpi, 2010). Similarly, being restricted to their bed or room, lack of privacy, being disturbed by other patients, boredom

due to lack of activities were recounted by children as the worst aspects of the hospital environment (Pelander and Leino-Kilpi, 2010). The social and physical environment of the ward was important to the children and was frequently mentioned by children when expressing their views of their hospitalisation (Sartain et al 2001; Coyne, 2006a; Carney et al 2003; Pelander and Leino-Kilpi, 2010). Interactions with other children and making friends were highly valued (Sartain et al 2001; Carney et al 2003) and for children who regularly attended the hospital the friendships and camaraderie that developed was a positive aspect of hospitalisation (Sartain et al, 2000). Initially children found it difficult to sleep due to poor ventilation, bright lights, the noise from telephones ringing, nurses talking, and babies and children crying but they talked about 'getting used' to the various adverse aspects of staying in hospital (Sartain et al, 2000). Children generally fitted in with ward routines even though they would rather have had more control over their day (Coyne, 2006a). Children appreciated nurses and their parents who helped to overcome some of the negative aspects of hospitalisation by caring, comforting, entertaining and being with them (Coyne, 2006a; Pelander and Leino-Kilpi, 2010; Coyne, 2015). Children were very conscious of their own space within the ward and spent time describing their bed and locker when asked about the ward (Carney et al, 2003). In contrast, other children reported being moved to different bed spaces on the ward or to different wards which impacted on their ability to form friendships with other children (Coyne, 2006a).

In a participatory study with children and young people, Lambert et al (2014) found that children wanted hospitals to be designed to have colourful, creative, comfortable interiors and access to outside spaces. Other important factors in

creating a good first impression for families on admission was to provide family friendly spaces, age-related play activities and shops. Children valued having space within their rooms and having items from home as well as the ability to personally control e.g. lighting, noise and privacy through the use of technology. Privacy was important so they recommended curtains at windows within bathrooms and toilets in addition to secure accessible storage for their food and drink. This study gathered views of children aged 5-8 years (*n*=55) using child-friendly approaches demonstrating that children in this age group can effectively articulate their views given appropriate opportunity. Data was to be collected through digital recordings of children's art based workshops within three hospitals but due to several practical problems a limited number of children were able to participate in the workshops (*n*=9) so data was collected in bedside, one-to-one activities or interviews. To demonstrate trustworthiness within this study the team provided a clear research audit trail; they collected contemporaneous electronic field notes following bedside activities/interviews; used a discussion guide within interviews; anonymously and independently undertook initial coding followed by team discussion and refinement of emergent themes.

Children have identified a range of ways that children's hospital admissions could be enhanced through changes to the environment (Lambert et al, 2013). Children expressed a desire for open access to a variety of different activities with spaces where they could participate in interactive leisure, entertainment, play and learning activities. Opportunities for children to be together and socialise were viewed as important but equally children valued the notion that there should be entertainment activities throughout the entire hospital that provided open access. The findings of this study reinforced the use of play to

minimise stress and anxiety whilst increasing opportunities to build rapport, self-esteem, cooperation, confidence and coping. Play offers fun for children as well providing familiar activities from their home lives. The use of technology within play and learning activities was a strong feature of the children's recommendations for enhancements in the environment. Connecting with others internal and external to the hospital were viewed as critical to improving children's socialisation with family and friends whilst in hospital.

The discussions incorporated within this section of the review have identified the impact of environment on children. The relationships became clear between environment and other aspects central to children's lives as findings were brought together. The great importance placed on environment by the children is in contrast to parental perspectives where environment did not feature as an over-arching theme. The differences in the children's and parental perspectives highlight the need for both children and parents' views to be sought when developing services. The place and the people emerge from the research studies as being key factors in children's experiences of hospital and the next section will now consider children's views of health professionals.

Children: health professionals

In the studies within this review the health professionals impacted both positively and negatively on children's experiences of hospital. Children clearly had expectations of health professionals and formed opinions of staff from their own observations and hospital experiences. In a descriptive qualitative study (Coyne and Kirwan, 2012), participants were recruited from three hospitals in Ireland ($n=55$); the sample included children with hospital experience, aged 7-18

years of age with acute and chronic illnesses. A strength of the data gathering in this study was the use of sentence completion and a 'three wishes' techniques (p295) to supplement interview questions and support children in their participation. All children did not wish to take part in these techniques so data was only collected using both methods from 38 children. It is not possible to determine from the paper whether the participatory techniques used appealed more to the younger children rather than the older ones and this could be useful for future study design. Children observed that doctors are people who diagnose and cure illnesses and perform procedures and operations (Coyne and Kirwan, 2012). Doctors were described positively as nice, smart, clever, funny and friendly people but children also commented that they could be a bit stressed, argue all the time and are too busy reading to talk to patients. Nurses were also described positively as nice, helpful, kind, gentle, pleasant, caring, funny, friendly who always listened but were strict. Both doctors and nurses were viewed as important people who provided medicines and who listened to children but children identified that student nurses had more time to talk to patients than other staff (Coyne and Kirwan, 2012). Researchers acknowledged that the wishes the children identified were focussed on issues covered in interview questions which may have influenced their choice. Raising awareness of certain issues through interview questions can bias children's responses either by bringing issues to the forefront of their minds, through their desire to provide correct answers or providing answers they believe interviewers are seeking.

It is evident that children seem to spend time observing and interpreting health care professionals' behaviours whilst they are in hospital and are well able to

articulate their opinions in detail when given the opportunity to do so. A qualitative study (Brady, 2009) captured children's views of good nurses using an adapted draw and write technique to interview children ($n=22$). There were some limitations as the sample did not include any children with limited ability to speak English, who were critically unwell or mentally or physically disabled. However, some rich data was collected that provides a detailed insight into children's perspectives. When describing 'good' and 'bad nurses' children seemed to bring together a range of information they had gathered about nurses which included their appearance, body language, verbal communication and stance (Brady, 2009). Children frequently talked about nurses who smiled or had 'smiling eyes' but they also believed that they could differentiate between types of smiles and sincerity of nurses' smiles. 'Good nurses' were identified as good communicators, they used special terms of endearment for children, provided prompt care and attention, acknowledged their feelings and praised bravery. Children were sensitive to tone of nurses' voices and body language, viewing 'good nurses' as ones that were nice, calm, cheerful, kind and did not shout. They also felt that 'good nurses' were willing to listen to them and spend time with them whereas 'bad nurses' were bad-tempered, bossy, angry, grumpy, moaned, shouted and did not listen to them. Children felt that nurses who were in a hurry would not be good when you were feeling ill and also felt that some 'bad' nurses walked quickly to avoid patients and they interpreted their haste as not being very careful in their work. This study identified a large number of attributes and behaviours that children listed as their expectations of children's nurses and some of these findings have been repeated in other studies. Children's interpretations of their observations of nurses were very interesting as they related nurses' behaviours in terms of themselves i.e. they

considered whether nurses liked or disliked them, and thought about how their own actions may affect whether the nurses liked them or not. Although this thesis did not set out to explore parental views of good nurses it could be useful for future research to find out similarities and differences in the way that parents and children interpret nurses' behaviours.

In Pelander and Leono-Kilpi's study (2004) children described some similar expectations of nurses to those articulated in Brady's study (2009) with children highlighting the need for nurses to show them respect by listening to the them. They also thought nurses should be safe in their work by checking on patients and being accessible. The sample in Pelander and Leono-Kilpi's study (2004) consisted of young children aged 4 to 11 years of age (*n*=40) with equal numbers of pre-school and school-aged children and equal numbers of children with hospital experiences with a chronic condition and an acute illness. Data collection methods involved short interviews with children with some accompanied by parents for support but not to interfere with their answers. Although researchers reported that they simplified wording of the questions to take account of participants' ages the quality of the data collected may have been further enhanced by using more child-friendly approaches, for example, more art based and participatory techniques. However, despite these potential drawbacks in data collection researchers did elicit important children's perspectives about nurses. Some children identified that nurses should be both caring and reliable, have a good sense of humour, be cheerful and wear colourful clothes at work (Pelander and Leino-Kilpi, 2004). They wanted parents and nurses to care for them in hospital but identified some activities that they saw as nursing activities- entertainment, education, caring and safety

whilst others were parental activities - to provide emotional support, relieve their fears and be company for them. Parental presence, other children and hospital activities were important to the children's positive views of the quality of their experiences (Pelander and Leino-Kilpi, 2004).

A number of studies within this review have highlighted similar expectations and attributes of health professionals from children's perspectives. In a study (Fletcher et al, 2011) that sought to involve young service users in health service planning, children and young people were asked their views about the skills, knowledge and attitudes that future children's nurses needed to have to care for children and families. This was a two-arm study collecting data initially from children with hospital experiences from two different hospitals ($n=61$) using children's participatory research techniques 'draw and write/tell' to elicit views, in addition to focus group data gathering with members of a local youth parliament. Limitations within the study are noted as a convenience sample of children with hospital experience was used and limited details of the sample mean it is not possible to determine whether some groups of children by gender, cultural background or age were under or over represented within the sample. However, despite these limitations the triangulation of the interview and focus group data provides useful findings with regard to children's views of nurses and hospital care. Findings were similar to those previously reported in that children generally want nurses to be competent, safe, practitioners who were also friendly. Children identified smiling as a fundamental attribute for children's nurses alongside good communication and inter-personal skills (Fletcher et al, 2011). Nurses were expected to be adept at delivering skilled care, providing distraction during procedures and keeping children pain free

whilst also being helpful and caring. A proportion of comments (8.2%) from children in this study (Fletcher et al, 2011) commented on fears relating to hospital acquired infections and potential for fake health professionals which perhaps reflects stories covered in the media around this time. It is interesting to note the impact that messages circulating within society and the media can have on children's perspectives but also on the aspects of experiences that may be a worry to them. Health professionals need to be cognisant of the range of worries that children may harbour as they are admitted into hospital in order to be able to provide genuine reassurances to them.

Children within the studies reviewed here provided many detailed and insightful comments about their experiences of being cared for by health professionals. Many studies focused mainly on nurses rather than all health professionals although medical staff were sometimes included. Participants have clearly identified characteristics of ideal nurses from their viewpoint and their detailed explanations of how they interpreted nurses' behaviours and made quality judgements from these observations are helpful.

This section has concluded the review of studies that focussed upon children's perspectives of their hospital experiences and the next section will explore themes within health professional perspectives.

Healthcare professionals' perspectives

Family-centred care incorporating parental involvement in care was generally accepted as the model of care adopted to deliver quality care for children and families within all studies reviewed and this was their key focus when exploring

professional perspectives. The professionals' perspective that was explored in the studies was that of nurses, although at times references were made to hospital staff or doctors. This focus is understandable given that nurses have greatest opportunity to develop relationships with parents as they provide care alongside parents during each day and night.

Key themes that emerged from studies incorporating health professionals' perspectives of care were: nurses' beliefs and perceptions; roles and relationships; power and control; difficulties in implementing family-centred care. These themes differ from themes emerging from the parents' and children's perspectives perhaps because the issues for professionals are quite different as care providers than the service users. Equally though the themes may reflect the focus of the studies themselves which are often controlled by researchers' agendas. The first theme to be explored within this section are professionals' beliefs and perceptions.

Professionals: beliefs and perceptions

The beliefs and perceptions of professionals emerged as a key theme and was seen as underlying professionals' actions and behaviours. Whilst family-centred care was acknowledged as the main approach to provision of quality care for children in hospital, continuing issues in its practice raised questions about nurses' knowledge and commitment to this philosophy of care.

In this review there was evidence suggesting that nurses had a good understanding of the components of family centred care and that nurses held broad and inclusive views of this approach, with families seen as central within

care (Coyne et al, 2011). Nurses believed it was best for children if parents were involved in care (Ygge, 2007; Coyne, 2015) and saw several advantages to parents being resident, for example, someone being with the child all of the time, providing care and comfort (Hughes, 2007; Coyne, 2015). It was also noted that nurses recognised parents themselves needed to be looked after by staff (Hughes, 2007). As previously noted within the parents perspectives' section of this review, nurses did not feel parents stayed with their child because they perceived nurses were too busy although this was what parents reported (Hughes, 2007; Coyne, 2007; Coyne, 2015). Nurses claimed they had no expectations of parents and thought parents stayed and participated in care for their own personal reasons or because they witnessed other parents doing this and felt guilty (Coyne, 2007).

Although nurses emphasised that parents were not required to stay with their child or participate in care, their own actions and behaviours suggested this was not the case in reality (Coyne, 2015). Nurses appeared to have implicit expectations that parents would stay with their child when they were in hospital and that they would be involved in care (Coyne, 2007; Coyne and Cowley, 2007; Ygge, 2007; Coyne, 2015). Nurses occupied a key position in the ward which enabled them to determine and control activities on the ward. Nurses' perception of their role and parents' roles influenced organisation of care and relationships on wards. Some nurses saw themselves as experts in care provision for ill children (Paliadelis et al, 2005) whilst others viewed their role as a supervisory one, supporting parents in care rather than providing direct care themselves (Coyne and Cowley, 2007). Emphasis was placed by some nurses on not taking over parent's role in parenting their child so after a period of time encouraging them to participate in care, nurses 'stepped back' and moved into a

more supportive role (Coyne, 2007). However, as nurses altered their position within the care scenario it appears that they did not openly discuss what they were doing with parents but chose to leave this to parents to interpret. Such lack of communication understandably led to some misinterpretations of nurses' actions by parents. In contrast, other nurses identified the importance of working collaboratively with parents and saw clarification of roles as one of their responsibilities (Ygge, 2007). Other nurses believed they should be the main communicators with the parents (Ygge, 2007) or act as interpreters between doctors and parents translating medical jargon into plain language for them (Paliadelis et al, 2005).

Findings discussed in this section have outlined the many different professional beliefs and perceptions regarding children's hospital care. There are some contrasting perspectives provided with regards to nurses' beliefs, expectations and behaviours which may send out inconsistent messages for parents within hospitals. The next theme to be considered appears as a major aspect of the studies reviewed and concerns roles and relationships.

Professionals: roles and relationships

The theme of roles and relationships is closely linked to the previous theme of beliefs and perceptions with each influencing the other in practice. Findings from reviewed studies revealed that nurses held different views on parental roles within care and in relationship to their nursing role. In many settings roles were not explicitly discussed with parents and therefore nurses' perspectives may dominate due to their professional position. In a qualitative study, Paliadelis et al (2005) used unstructured interviews with nurses to explore their

perceptions of how they included and involved parents in their child's hospital care. Although researchers stated that participants were purposively selected from two different hospitals and include nurses with a range of diverse experience there are no further details of this diversity in nurses' backgrounds, level of experience and seniority and this may have influenced the findings. Researchers acknowledged that this study could have been further enhanced through observations and exploration of other stakeholder perspectives. However, despite these limitations, findings provide some important perspectives that are consistent with previous literature (Espezel and Canam, 2003; Shields et al 2003; Shields et al, 2004, Shields et al, 2006) in addition to contributing to understanding of nurses concerns in relation to parental involvement. For some nurses there was clear delineation between tasks perceived to be the nurses' role and others that could be allocated to parents provided they were deemed competent by the nurses (Paliadelis et al, 2005). Tasks would only be given to parents if the nurses felt that parents were competent and willing to participate. To some extent nurses appeared to be protective of parents, feeling strongly that parents should not be expected to take on nursing tasks as they felt their focus should be fully on their child. However, there was also a sense of protection of their own professional roles as well as concern for parents (Paliadelis et al, 2005). Nurses felt responsibility for safe care of children and appeared to focus more on technical and clinical aspects of care than psycho-social aspects of care (Paliadelis et al, 2005; Coyne, 2007).

The extent to which parents were involved in their child's care was largely controlled by nurses many of whom believed that parents were mainly there to

be with their child and provide comfort (Paliadelis et al, 2005). Nurses felt appropriate parental roles involved: being with their child; providing comfort and reassurance; personal care; help with feeding and elimination; entertainment and advising nurses of changes in child's condition (Paliadelis et al, 2005). Other more advanced tasks such as giving medications, changing dressings and recording fluid balance were only considered appropriate for parents to undertake if they had been trained and assessed as competent (Paliadelis et al, 2005). Coyne (2015) reported similar findings in that nurses' trust in parent's competence in clinical care had to be developed noting that parents of chronically ill children were treated differently in relation to their involvement in care. Nurses in Paliadelis et al's study (2005) talked about adopting a protective role to parents and this appeared to be used to justify their exclusion of parents from situations that they felt would be too distressing for parents. It is not possible to ascertain from this study's findings whether nurses actually did act this way in practice and if they did, how their behaviours were interpreted by parents. There is a sense here of nurses perhaps believing they know what is best for parents and acting in their best interests whilst actually disempowering them by depriving them of the option of deciding for themselves what might be best. An alternative viewpoint would be to challenge nurses' stated motivation for their behaviours and to consider that nurses may actually be exploiting their own position, consciously or unconsciously, for other reasons, such as beliefs about parent and nurses' roles, timing or speed of carrying out procedures without parental involvement or even lack of confidence in carrying out distressing procedures under parental scrutiny. It is possible that nurses' interview responses may be influenced by a level of desirability bias, this is where participants provide interviewers with responses that present a

more positive picture to interviewers or matches what they think is wanted by the interviewer. Paliadelis et al's study (2005) was undertaken within hospital settings where the care occurred within territory familiar to professionals rather than parents and this may have influenced nurses' perspectives. In addition, findings suggest that some nurses limited the extent of parental involvement unless parents needed to deliver on-going care at home, further supporting the notion that nurses rather than parents drive and control the way that parental participation occurs.

Nurses working with parents of children with on-going care needs may approach parental involvement in care differently to the nurses in Paliadelis et al's study (2005). In a recent qualitative study (Panicker, 2013), exploration of nurses' perceptions of parental empowerment in relation to the care of their chronically sick child was undertaken. There were some interesting differences between the findings of these two studies, for example, Paliadelis et al (2005) reported that nurses raised safety issues as a main reason for limiting the extent of parental involvement in care, whilst Panicker's findings (2013) identified that nurses believed that through empowerment parents could provide safe and organised care for their child at home. Nurses described using a range of strategies to empower parents including: increasing parental knowledge and skills in relation to their child's condition; providing them with support services; developing a trusting environment with effective communication channels; support and shared decision making (Panicker, 2013). It was suggested that barriers to empowerment were lack of resources such as time, facilities, support services and experienced staff but also included differing expectations between parents and professionals mainly rooted in

limited shared decision making and honest communications. It has been proposed that in the absence of successful negotiation of roles within a child's care, more controlling and disempowering practices can potentially emerge (Newton, 2000; Espezel and Canam, 2003; Shields et al 2006; Coyne, 2007). In contrast to the nurses in Panicker's study (2013), nurses within Paliadelis et al's study (2005) described behaviours that could be considered as a protective, paternalistic approach towards parents but equally they could be interpreted as disempowering and controlling behaviours.

In the studies reviewed, parental involvement in care often focused on nurses' partnership with mothers with limited mention of fathers. However, Higham and Davies (2012) explored the role of fathers in an ethnographic study finding that fathers participated in their child's care in a multitude of ways but this was largely unrecognised by nurses except when resident with their child. It was expected by nurses, mothers and fathers that fathers would stay with their child and participate to some extent. Parents themselves saw the mother as the main carer believing that the mother-child bond gave them priority and allowed them autonomy in decision making compared to fathers who often had to defer to mothers. Fathers generally did not feel involved in clinical decision making but equally did not feel well-equipped to be involved in such decisions. Their role was characterised by protecting, providing for the family and participating in care. Fathers sometimes worked as well as ensuring the needs of the mother and the rest of the family were met, bringing in food and clothes for mother and child. They provided routine childcare for the sick child in the same way that mothers did, in addition to caring for siblings. Fathers also felt their role was to 'be strong' , provide emotional support and to advocate for the mother and sick child in circumstances where their needs were not adequately met.

The discussion of the theme in this section of the review has identified some central issues relating to parental and nursing roles within family centred care. Variation in views from paternalistic protection of parents to empowering relationships with parents demonstrate complex dynamics involved in care provision using this approach in practice. Issues of professionals' power and control within these relationships has been mentioned earlier in discussions but will be explored further within the next section.

Professionals: power and control

A dominant theme within the literature relates to underlying use of power by nurses to control parental behaviour within hospital settings, a concept that seems at odds with a family centred care philosophy based on partnership working and parental involvement in care. In effect, it seems that there may be a level of pretence with regard to equality and partnership between nurses and parents and underneath the surface there may be elements of role conflict. Differences in the position of nurses and parents may further influence the power balance that exists: nurses hold professional power and information whilst been comfortable within hospital environments whereas parents may feel anxious and vulnerable because of their child's illness and admission. Power and control issues were uncovered within Coyne's research (2007) when nurses purported to uphold the central philosophy of family centred care and partnership working with parents but their actions would sometimes contradict their stated beliefs. Rather than promoting collaborative relationships and empowering parents to be true partners in their child's care nurses actually used a range of strategies to socialise and control parental behaviours within wards

(Paliadelis et al, 2005; Coyne, 2007). Nurses assumed control of decision making within children's care by teaching, informing and advising parents about their child's treatment and care whilst establishing that parents must seek nurses' permission before taking decisions. Parents were discouraged from taking on responsibility for anything other than the most basic tasks unless it was considered that they would need to learn specific nursing skills to continue care at home (Paliadelis et al, 2005). Similarly, control of parents' actions and behaviours on wards was explicitly described as the socialisation of parents (Coyne, 2007) whereby nurses used various tactics to manage parents. It was reported that nurses expected parents to be with their child, behave well and provide some nursing care. Parents who followed nurses' directions, co-operated and were undemanding met the nurses' expectations of them and were rewarded by further personal attention. Parents who deviated from implicit sets of rules and norms held by nurses were seen as problematic, difficult parents and efforts were made to persuade, educate and advise them of acceptable behaviours but if this failed an exclusionary approach was taken and nurses avoid them.

In Paliadelis et al's study (2005) the researchers also noted the powerful position that nurses held within wards and how they controlled parental involvement. Nurses' spoke of 'allowing' parents to take part in care demonstrating their view of themselves as being in charge of these decisions. Nurses assumed control of decision-making processes for children's care and parents were to ask nurses' permission before making care decisions thus underlining nurses' position as superior to parents within the ward hierarchy. Nurses discouraged parents from assuming responsibility for anything other than basic parental duties and nursing skills were only taught if parents needed

advanced skills to provide home care (Paliadelis et al, 2005). The rationale nurses gave for their attitude and actions was that they were protecting parents who were often tired and distressed and needed to focus on providing emotional comfort to their child. In this study, it was only nurses' beliefs and practices that were explored so it is not possible to ascertain how parents felt about nurses apparent protection of them. Potential for misinterpretation of each others' motivations and behaviours within nurse-parent relationships seems highly likely where open communication between parties is absent as seems evident in Paliadelis et al's study (2005).

This section of the review has demonstrated a range of issues relating to the power and control exerted by nurses within nurse-parent relationships. Findings showed that nurses were able to use their position and knowledge to control the extent to which parents were involved in their child's care or how parents behaved. The final section of this review considers the theme relating to difficulties in implementing family centred care.

Professionals: difficulties with family centred care

Findings of the reviewed studies highlighted various difficulties in implementing family centred care and this reflects debates in the literature for many years now. Nurses reported implementation problems even when they appear to fully understand the requirements of this approach and it has been suggested that this may be due to lack of organizational, managerial support and resources (Coyne et al, 2011). Challenges in implementation of this model of care have been reported, including; lack of negotiation, lack of appreciation of the impact of families on nurses' workload, poor facilities for families, lack of emotional and

social support for families, poor documentation and communication aids and lack of educational programmes and workshops about this core element of children's nursing (Coyne et al, 2011; Coyne, 2015). Earlier findings support these difficulties with implementation of this model of care listing similar concerns relating to burden of administrative work, heavy workloads and inadequacies in both resources and facilities (Paliadelis et al, 2005; Ygge, 2007). Differences were noted between how experienced and newly qualified nurses worked with parents on wards (Ygge, 2007). Nurses who felt secure in their own level of competence seemed more able to concentrate on developing relationships with families whilst novice nurses tended to focus on tasks resulting in less engagement with providing information, demonstrating, responding to parents' questions and dealing with their anxieties (Ygge, 2007).

Paliadelis et al (2005) identified further barriers to implementation of parental involvement in care as: poor communication between nurses and parents; lack of confidence in their professional or parental roles; nurses concerns about legal accountability for care; lack of supportive structures and guidance and nurses' experience of managers reducing staffing levels in the belief that resident parents decreased workloads. Furthermore, some nurses were seen as being too overworked, tired, de-motivated and burned-out to teach and involve parents in care whilst others were merely reluctant to share their professional expertise (Paliadelis et al, 2005). However, main constraints were perceived to be lack of time to be with children, form relationships and educate, support, communicate and negotiate with parents (Paliadelis et al, 2005, Sarajarvi et al, 2006, Shields et al, 2006; Ygge, 2007; Coyne, 2015).

This final section of the literature review has outlined a range of potential reasons provided for the difficulties encountered by nurses in implementing

family centred care. These fundamental problems continue to impact on provision of hospital care for children that is truly family centred. To conclude this review key themes from the parents' perspectives, children's perspectives and health professionals' perspectives will now be discussed.

Discussion and Conclusions

The dominant current philosophy of care in children's nursing is family centred care incorporating parental involvement. This review found that children wanted their parents to be with them and participate in their care when in hospital: equally, parents and nurses supported this approach to care, seeing it as beneficial for both child and family (Sartain et al, 2001; Espezel and Canam, 2003; Stratton, 2004; Hughes, 2007; Higham and Davies, 2012; Coyne, 2015; Peeler et al, 2015). Despite these apparent shared beliefs relating to parents and nurses delivering care to hospitalised children, operationalising such partnership working in practice was found to continue to be problematic for both parties (Paliadelis et al, 2005; Ygge, 2007; Coyne et al, 2011; Coyne, 2015). Reforms of children's hospital care following the Platt Report (Ministry of Health, 1959) over several decades, is reflected in contemporary health policy and guidance, therefore, parental presence on wards and the need for nurses and parents to work together to care for hospitalised children will continue. It is, therefore, imperative that we fully explore parents' and nurses' perspectives of care experiences to understand aspects of the experience which are valued and those that cause difficulty, to enable future improvements to occur in practice. This literature review demonstrated differences in parents', children's and professionals' perspectives thus re-enforcing the need for further investigation

to fully appreciate where tensions and disconnects exist that may impact on judgements of quality care provision. Parents' perceptions of quality as a service user are significant and it is essential that factors that will potentially impact positively or negatively on their evaluations are appreciated and addressed.

Parents' accounts describe the many disruptions to their lives caused by their child's hospitalisation and many parents felt they did not know what was expected of them in hospital (Sartain et al, 2001; Coyne and Cowley, 2007; Hughes, 2007; Tong et al, 2010; Higham and Davies, 2012; Coyne, 2015; Peeler et al, 2015). Parents reported feeling anxious and stressed when their child was hospitalised but the extent of the fear and worry experienced by some parents was not always fully recognised by nurses (Phua et al, 2005; Coyne and Cowley, 2007; Avis and Reardon, 2008; Matziou et al, 2011; Wray et al, 2011; Peeler et al, 2015). Parents and nurses held different views about why parents stayed with their children in hospital. Many reasons were given by parents for staying with their children in hospital, they felt they needed to 'be there' for their child; provide emotional reassurance; provide some normality for them whilst comforting, distracting and entertaining them (Sartain et al, 2001; Coyne and Cowley, 2007; Coyne, 2015). Others stayed to keep their child safe, by watching over them whilst others felt obliged to stay because it was expected of them, they saw the nurses were too busy or felt that their child would not receive the correct care unless they stayed (Hughes, 2007; Coyne and Cowley, 2007; Avis and Reardon, 2008; Cox et al, 2013; Coyne, 2015; Peeler et al, 2015). In contrast, nurses perceived that parents stayed with their children because they wanted to be with them; needed to fulfil their parenting role or saw

other parents staying and felt guilty if they did not stay (Hughes, 2007; Coyne, 2007).

Communication and especially information provision was found to be a key determinant of parental satisfaction with care (Ammentorp et al, 2006; Co et al, 2003; Matziou et al, 2011; Byczkowski et al, 2013). Parents arriving in hospital ward with their child may have had previous hospital and illness experiences that impacted on their perceptions and expectations of their current admission and affected their interactions with staff (Espezel and Canam, 2003; Phua et al, 2005; Avis and Reardon, 2008). Parents needed professionals to communicate effectively with them and provide them with understandable information to reassure and enable them to participate in care (Sartain et al, 2001; Espezel and Canam, 2003; Coyne and Cowley, 2007; Stratton, 2004; Coyne and Cowley, 2007; Avis and Reardon, 2008; Matziou, 2011; Solheim and Garratt, 2013). The degree to which parents wished to be involved in care varied dependent on their child's condition, their previous experience and expertise (Sartain et al, 2001; Phua et al, 2005; Avis and Reardon, 2008). Parents valued interactions with professionals and the development of a rapport or relationship with professionals was found to be helpful to parents as they tried to cope with their child's illness and hospital experience (Espezel and Canam, 2003; Stratton, 2004; Matziou, 2011).

Parents were reticent about querying nurses' practice and did not want to be labelled as difficult or problem parents so tended to be compliant with the staff's wishes and expectations. Some parents were not deterred by these potential issues and went ahead and raised their queries or requests to rectify what they perceived as inadequacies in care provision (Simons, 2002; Tong et al, 2010; Higham and Davies, 2012; Peeler et al, 2015). Lack of communication,

negotiation, explanation and sensitivity to parents' emotions and needs impacted on parents' experiences and perceptions of care quality. There appears to be a sub-text within findings of the reviewed studies relating to concerns, queries and dissatisfaction from parents' perspectives and demanding, troublesome parents from nurses' perspectives (Simons, 2002; Coyne, 2007; Coyne and Cowley, 2007; Tong et al, 2010; Higham and Davies, 2012; Coyne, 2015; Peeler et al, 2015). Nurses' perceptions of parental and nursing roles, reliance on parents to participate in care and their efforts to socialise and control parental behaviours on the wards has been documented (Paliadelis et al, 2005; Coyne, 2007; Coyne and Cowley, 2007; Coyne, 2015). However, less is known about views, actions and behaviours of parents within these complex social situations and additional investigation in this area may uncover more details of parental motivations and behaviours that are only hinted at within the reviewed studies. Additional exploration in this area may provide critical understanding of factors influencing effective parental and nurse relations and perceptions of quality care.

This review found that children were similar to their parents in terms of being anxious and harbouring fears and worries about being in hospital (Carney et al, 2003; Coyne, 2006; Pelander and Leino-Kilpi, 2010; Fletcher et al, 2011; Ford, 2011; Coyne and Kirwan, 2012). However, the children's accounts suggest that positive experiences; making friends; personalising space and effective social and emotional support from parents, family and staff helped them to cope with their fears and enjoy some aspects of their stay (Sartain et al, 2000; Carney et al, 2003; Coyne, 2006a; Pelander and Leino-Kilpi, 2010; Ford, 2011; Coyne and Kirwan, 2012). Children's priorities reflected their immediate concerns and therefore altered dependent on their current situation. Children were well able

to articulate their views: initially, concerns focussed on their fears and worries but moved on to their surroundings, the people they were interacting with and hospital activities. The immediacy and concrete nature of children's concerns contrast with their parents who had anxieties based in past, present and future. Children were observant and sensitive to the actions, verbal and non-verbal behaviours of nurses and some associated the way they were treated with their perception of whether or not staff liked them (Pelander and Leino-Kilpi, 2004; Brady, 2008; Fletcher et al, 2011; Coyne and Kirwan, 2012). It is interesting to note how children interpreted nurses' behaviours in these studies and inferences they made from nurses' actions. Further research to explore the nurses' and children's perspectives of the same situations may offer new understanding of how to promote positive interactions with minimal discrepancy between nurses' behaviours and children's interpretations.

Children identified that they wanted prompt, competent care delivered by nice, cheerful, friendly staff who would show genuine interest in them (Sartain et al, 2000; Sartain et al, 2001; Carney et al, 2003; Coyne, 2006a; Brady, 2009; Pelander and Leono-Kilpi, 2004; Pelander and Leino-Kilpi, 2010; Lambert et al, 2012). The notion that some nurses may be perceived by children as not showing genuine interest in them is worthy of further investigation to determine the characteristics and behaviours children use in forming these judgements. Equally, exploration of this concept with parents may be helpful to discover if parents are similar to children in how they make such judgements.

Nurses, similar to parents and children believed it was best if parents were resident and involved in care although the extent to which parents were involved in care seemed to be controlled by nurses, in the same way that nurses attempted to control parents' behaviour generally on wards (Paliadelis et

al, 2005; Coyne, 2007; Coyne et al, 2011; Coyne, 2015). Within the studies reviewed there is evidence of underlying tensions in nurse-parent relationships and future exploration of these tensions is worthy of investigation to better understand the complexities involved in the social interactions within children's hospital care.

In this review a number of primarily quantitative studies reported on survey data (Simons, 2002; Co et al, 2003; Chesney et al, 2005; Miceli et al, 2005; Phua et al, 2005; Ammentorp et al, 2006; Sarajärvi et al, 2006; Ygge et al, 2006; Hughes, 2007; Matziou et al, 2011; Williams et al, 2011; Wray et al, 2011; Byczkowski et al, 2013; Cox et al, 2013; Solheim and Garratt, 2013) often using large representative samples and national databases, some statistically significant findings demonstrating correlations between different constructs, for example, overall satisfaction with care, identified elements of care and parental priorities in care provision were evident. Survey findings provided clear, numerical data about parental satisfaction levels and in many studies parents were found to be generally satisfied with care although it was not possible from the data to determine further details, for example, why some parents were satisfied and others not or why some areas were deemed more important by parents than others. Whilst these studies offer important generic information to support quality care evaluation and improvements they do not provide a complete picture of the situation as they are unable to give explanations for parental responses. It is findings from qualitative studies that delved more deeply into parents', children's and nurses' perspectives that shed light on the complicated nature of hospital experiences. Insights provided by such in-depth exploration is most valuable in revealing factors impacting on parents' perspectives of quality hospital care which health professionals need to be fully

cognisant of when providing care. Further in-depth investigation of parental perspectives of the quality of their child's hospital care would potentially give a more comprehensive view of the influences on parental judgements of quality. Without understanding underlying influences on parental perceptions of quality of care it is difficult to determine where improvements need to be made to improve their experiences as service users.

Conclusions

This review has synthesised research findings from selected studies relating to parents' and children's experiences of hospital care and quality of care and health professionals' perspectives. Key messages from children's perspective were that hospital admission caused much disruption to their normal lives and prompted them to be fearful and worried but these feelings could be alleviated through effective psycho-social support, positive experiences of hospital and interactions with staff, maintenance of links to their normal lives through relationships with family, friends and personal items and activities. An important aspect of the studies was recognition that children wanted their parents' support and involvement in their care. Generally children's needs were met either by their parents or nurses and they seemed happy with this arrangement. However, children did not appear to be aware of some of the difficulties encountered by parents and nurses as they attempted to work together to provide care. Future studies to explore children and young people's perceptions of the roles of nurses and parents may help in understanding this phenomenon.

The central theme dominating the discourse within both parents and nurses perspectives related to roles and relationships as they found themselves brought together by the child's hospitalisation. Although both parties appeared to agree that a family centred approach to care involving parents in their child's care was best practice, the achievement of this in reality proved difficult. Lack of communication and negotiation between parents and nurses seemed to provide many opportunities for misinterpretation of behaviours and potential sources of tension and disharmony. Nurses held a powerful position and tried to control parents behaviours through managing the extent of parental involvement and use of strategies to ensure their compliance with expected norms. Some parents' accounts intimate difficulties and dilemmas in raising any queries or concerns they had, about their child's care and treatment with professionals although this was not fully explored and defined within these studies.

It is evident from this review that gaps exist in the knowledge base about parental perspectives of the quality of their child's hospital care. Further qualitative investigation of parental perspectives would enable a fuller appreciation of the complex factors influencing judgements of quality of care and greater understanding of parents' behaviours. The research study reported in this thesis aims to contribute to this knowledge base to inform future developments in children's hospital care.

The study's aims and research questions are provided here:

Aim and research questions

The aim of this study is to explore the parental perspectives' of the quality of care provided when their child is hospitalised.

Primary research questions:

How do parents determine the quality of the care provided when their child is admitted to hospital?

Do parents perceptions of their child's hospital care change over time?

What factors influence parents' perceptions of the care?

Secondary research questions:

How do parents make judgements about the quality of care provision?

What factors influence parents' judgements of the components of quality care?

Which aspects of care do parents find most and least important when judging whether or not care is of high quality?

Chapter 3: Methodology - philosophical and theoretical approaches

Introduction

This chapter outlines the research paradigm within which this study is set and philosophical underpinnings of the research undertaken. The original sources of my personal curiosity about quality care for children are briefly re-visited. The epistemological and ontological stances are explored and discussed and rationale for using a constructivist grounded theory approach provided. In this chapter, the following sub-headings form the framework for the discussions: background to topic choice; research paradigms, philosophical and methodological approaches; Grounded Theory.

Background to topic choice

At the outset of this thesis my personal background was outlined and critical personal experiences shaping my ideas for this study shared. It may be useful here to re-visit these aspects briefly before considering the decisions that then occurred to move these ideas and ideals into the research study that is reported on in this thesis. The main personal motivation which has underpinned all of my work in children's nursing has been to improve the quality of care for children and their families. My previous clinical experience in hospital care of children and my acknowledgement of the unique position of parents when their child is in hospital, has also played a part in the way my ideas evolved for this study. The critical incident that arose from the receipt of a complaint letter from a parent

brought a fuller appreciation of how an event viewed from different people's perspectives created multiple realities. It is often only by appreciating other perspectives of situations that progress and improvements can be made. It was from my personal background, existing literature in adult care and gaps in children's healthcare literature relating to quality evaluations and parental perspectives of quality care that determined that this was an area for further exploration. The study presented potential opportunity to identify quality aspects of care from parents' perspectives that may have previously eluded measurement through traditional positivist methods such as, satisfaction scales, quality measures and professionally determined standards.

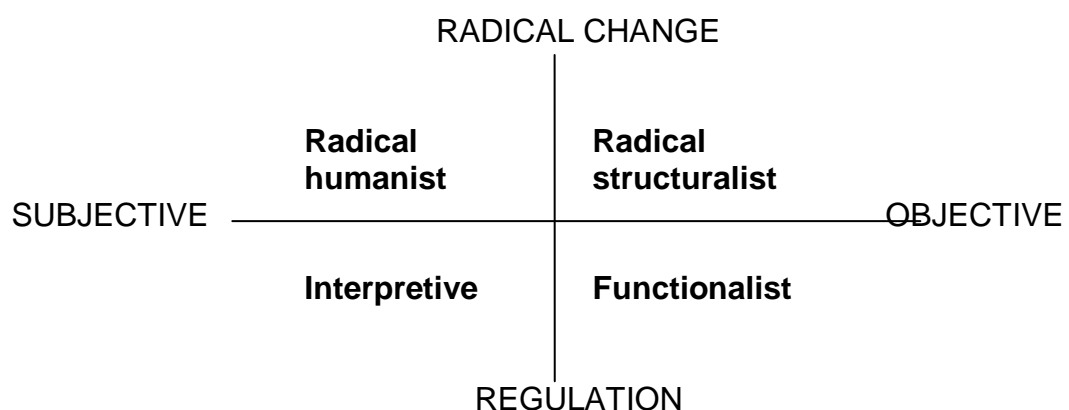
Research paradigms, philosophical and methodological approaches

The research paradigm within which a study is undertaken reflects the researcher's personal world view and also acts as a bridge between the aims and methods of the study (Creswell, 2013). Houghton et al (2012) supports this notion, seeing the identification of the research paradigm for the study as critical, recognising that it underpins research design. There are various definitions and classifications relating to research paradigms (Parahoo, 2006; Denzin and Lincoln, 2008; Crotty, 1998; Blaikie, 2007; Weaver and Olsen, 2006) but key components identified relate to :

- ontological position - this concerns beliefs about the nature of reality
- epistemological position - the nature and reality of knowledge
- axiological position - the relationship between the researcher and participants
- methodology - the way to conduct research with regard to research questions and context

Burrell and Morgan (2006) proposed four separate paradigms identifiable within social theory: radical humanist; interpretive; radical structuralist and functionalist. These paradigms reflected differences in beliefs about the nature of reality whereby at one end of the continuum reality is thought to be constructed by the person experiencing it (subjective) and at the other end, the belief is that reality exists externally to individuals and consists of concrete, tangible structures (objective). In addition, they recognised another continuum where individuals' desire to understand and explain existing society (regulation) was at one extreme and a concern for emancipation from current social structures and potential alternatives to the status quo (radical change), lay at the other extreme. Burrell and Morgan (2006, p.22) encapsulated these concepts within a matrix formed with two intersecting axis representing the two continuums: subjectivist - realist and regulation - radical change, and the four paradigms of social theory were housed within the quadrants (see Figure 1).

Figure 1. **Burrell and Morgan's Social Theory Matrix**



Central debates underlying these differing perspectives and forming the basis for the matrix relate to different ontological, epistemological and axiological perspectives:

- the nature of knowledge (epistemology) and whether the social world can be understood from an observer or outsider viewpoint or whether it needs to be experienced
- the notion that people are autonomous, having the choice to make changes or that the environment determines the individual and their activities
- the belief that developing understanding of the social world is dependent on close encounters with the phenomena under study through insider perspectives and detailed analysis of individual accounts or that such understandings will be best achieved through adoption of approaches used within the natural sciences focussed upon experimental design

My personal worldview in relation to Burrell and Morgan's matrix (2006) best fits within the interpretivist/social constructivist paradigm reflecting a subjective position on the nature of reality and an interest in understanding the current social world from the individuals' experiences of it. Adopting a social constructivist approach enables the researcher to appreciate the phenomena under study through subjective perspectives of those directly involved. The epistemological assumption within social constructivist- interpretivist research is that the knowledge gained from bringing together the subjective experiences of individuals is an appropriate and legitimate form of knowledge (Creswell, 2013).

The social constructivist worldview is based upon a belief that our world is socially constructed and that we are involved in a continuous process of interpretation of our environment and interactions that take place within it to help us to appreciate and understand it (Milburn et al, 1995; Mertens, 2005). Social constructivists believe that full understanding of human behaviour is

embedded within social interactions and the way that people then interpret and apply meaning to these interactions (Todres and Holloway, 2006). Researchers working within this paradigm seek to discover the individuals' subjective meanings of these experiences. There is acknowledgement within this approach that such meanings are developed through both interactions and cultural and historical norms (Creswell, 2013). Participants' accounts are central to this type of research and theory is inductively generated. Researchers recognise their own position within the research as their personal background and experiences influences their interpretation of the data gathered. Social constructivist methodological approaches not only accepts but embraces researchers' existing knowledge and experience viewing these individual 'human' elements of the researcher to be both inevitable and valuable (Appleton 1997; Guba and Lincoln, 1989; Koch, 1999; Shah and Corley, 2006).

The social constructivist paradigm offered different methodological approaches for consideration in addressing the research aims of this study, for example, ethnography, phenomenology and grounded theory. There were a number of aspects of the ethnographic research approach that were relevant to the topic under exploration. In ethnography, the focus is on the study of human behaviour in cultural terms and the aim within this approach is to create a picture of the people within a specific cultural group (Creswell, 2013). The central belief is that human behaviour is influenced by the setting or culture in which the participants live, understanding their way of life from their perspective is key to producing a cultural description of the group under study. Ethnographic studies offer a broad view of a setting or culture and aim to discover new, unpredictable, unknown or unexpected findings (Hunt and Symonds, 1995).

Such studies can develop a rich, deep understanding of social behaviours of a group or a culture-sharing group (Wolcott, 2008). These elements of ethnography initially seemed appropriate for the research topic, however, the notion of the parents as being a culture sharing group with established patterns of shared behaviours appeared to be less relevant to these participants. In practical terms the ethnographic researcher is required to spend extended periods of time as an observer within the area to immerse themselves in the culture (Creswell, 2013) which also posed many pragmatic time and access challenges. This approach is best suited to describe and interpret shared patterns of the culture of a group and whilst such rich description of social behaviours within hospital settings were desirable the intent of the study was to go beyond a descriptive level. It was for this reason as well as resource and access implications that resulted in this methodology being rejected.

Phenomenology was also explored as a potential methodology for the study. Whilst there are variations within phenomenology, transcendental and hermeneutical approaches are most commonly used within nursing research studies (Todres and Holloway, 2006). Both approaches value full description of the lived human experience of a phenomenon and aim to capture and communicate the essence of the experience. The focus is to develop understanding of a common meaning for several individuals of their lived experiences of a phenomenon (van Manen, 1990). Transcendental phenomenology is founded on the philosophical views of Husserl (1931), this approach adopts a subjective, inductive approach which at its inception completely contrasted with the dominant research paradigm of the time which valued positivist, objectivist research approaches. Husserl (1931) believed that

phenomenologists needed to suspend or 'bracket' their existing knowledge of a phenomena as they gathered description of the individual's conscious experience of the phenomena. Heidegger (1962), a student of Husserl, went on to develop hermeneutic phenomenology which is underpinned by the philosophical belief that it is an individual's interpretation of the everyday world that is at the foundation of human understanding.

Researchers using both approaches aim to present a clear view of the phenomenon from the perspective of those who have experienced it - this is described by Moustakas (1994) as the "what" and the "how" of the experiences. However, a fundamental difference in the two versions of this methodology lies in the beliefs about the role of the researcher's personal biases and knowledge of the topic area. Transcendental phenomenology uses the term 'bracketing' to describe the way that researchers are expected to put aside their own personal beliefs, prejudices and preconceptions whilst conducting the research (Moustakas, 1994). Capturing the individual's 'lived experience' as impartially and accurately as possible through 'bracketing' is seen as important in this approach (Giorgi, 2009), although it is recognised that this is rarely really ever achieved (Moustakas, 1994). In hermeneutic phenomenology the researcher writes a description of the phenomenon and provides an interpretation through their mediation between different meanings (van Manen, 1990). Researchers following this approach do not bracket their personal biases or previous knowledge but acknowledge them and may use their existing preconceptions as a way of 'sensitising' themselves to notice particular differences and omissions in the descriptions.

Phenomenological approaches did offer the opportunity to capture the parents' lived experiences of their child's hospitalisation through description and

interpretation. However, this did not fully fit with the study's intent which was to go beyond such description and interpretation to provide explanation through the generation of theory in relation to parental judgements of quality in children's hospital care. It was evident that this first step in choosing the methodology had required consideration of my own philosophical viewpoint and this process revealed my position as a researcher and the various influences from my clinical career in children's nursing and past exposure to different research approaches. The philosophical viewpoint taken in the planning of research has a major influence on all aspects of any study from the methodological approach to the data analysis and reporting of the findings (Lacey, 2006).

Ethnography and phenomenology both had potential to offer interesting insights into the topic area but were rejected as constructivist grounded theory provided the best fit with the study's aim, ability to support the research focus, address the research questions and compatibility with my own philosophical viewpoint. The central focus of this study was to capture and understand the parents' perspective on quality in their child's hospital care. It was their interpretation and reactions to the experiences that were important and therefore the ownership and expertise lay with them. My role as a researcher was to explore and gain understanding of the parents' personal reality by in-depth exploration of their experiences. The desire to appreciate the socially constructed meanings assigned to their experiences and the psycho-social processes underlying their behaviours underpinned the choice of grounded theory as the most relevant methodology for this study.

Holloway and Wheeler (1996,p100) have previously commented that,

Grounded theory helps healthcare professionals to give up their own model of patient care and disease management in order to adopt an alternative perspective based on the perceptions and beliefs of patients." (p100)

Similarly, in this study, it was envisaged that the construction of a theory created out of data from parental perspectives would enable health professionals to see their familiar world through parents' eyes. Exposure to this different perspective and reality may prompt adjustments to their own future views and behaviours to benefit children and families. The development of a grounded theory relating to quality in children's hospital care would add a new dimension to existing knowledge where the previous focus has mainly included adult patients or professional perspectives.

Grounded theory

Grounded theory has its basis in symbolic interactionism which was first described in the 1920s and 1930s (Mead 1934). Symbols within human interactions were viewed as a central aspect to human life. These notions were further developed from a theoretical perspective (Blumer, 1969) and drew attention to how people acted with each other: taking notice of each other's behaviour and 'reading' and interacting with others. According to Blumer (1969), where alterations in behaviours occurs meanings are re-interpreted. This process of interaction and the way in which people understand their roles features heavily in this sociological approach. Within grounded theory this idea is evident in that people are seen as being active within their experiences through their interpretation of situations and then their reactions based on their interpretation of the event/interaction. The study and analysis of the

interactions and responses to one another provides raw data for development of a grounded theory (Holloway and Todres, 2006).

In this study an important element for exploration related to parents' experiences of care of their hospitalised child and how they made sense of these experiences. In particular, the way that their interpretations of their experiences related to their judgements of whether care was perceived as high quality or not. A transformation of views over time and reluctance to complain about poor quality care is evident in the adult literature on this topic (Edwards et al, 2004) but had not been previously explored within children's hospital care. It was important, therefore, to explore parental responses to their experiences and to determine if parents, similar to adult patients, might alter their opinion of quality of care provision as time elapsed since the experience. The need to explore both interpretation and responses of parents fitted well with the symbolic interactionist basis of the grounded theory approach adopted in this research.

The theoretical perspective of symbolic interactionism depicts human beings as developing and being socialised as they grow up and learn how to act in accordance with the expectations of others. Furthermore, individuals analyse the symbols of others such as language, gestures, and appearance and interpret them. To understand action and interaction researchers have to look at the meanings human beings give to it. In grounded theory, researchers explore these meanings and the 'definition of the situation' by those observing and living in it and the context of the situation is seen as crucial to understanding. This again fitted well with the research aims where importance

was placed on the parents as the ones that were experiencing the situation of their child requiring hospital care. Through analysis of their interpretations of their interactions and the meanings they assigned to these experiences it was envisaged that a more comprehensive understanding of the situation would emerge.

Grounded theory stresses the importance of context in which people function and share their social world with others whilst symbolic interactionism focuses upon finding out and understanding the way meaning is attributed in social situations. Denzin (1989) identifies symbolic interactionism as showing the connections and processes existing between people and society through the medium of symbolic communication. Mead (1934) had described the way that humans use symbols to denote objects allowing shared meanings and communication to take place. Individuals attach different meanings to the same objects and an individual will experience the different meanings they hold for others reflected back to themselves. To handle this complexity the individual constructs a picture of themselves according to the predominant view they are shown by others. This is carried out largely through the medium of language and through exchanges people learn how they are expected to act in a social world. The hallmark of symbolic interactionism is the explanation of such processes leading to an understanding of how and why things are as they are, by finding out about people's life circumstances (Blumer 1969; Milliken and Schreiber 2001). This study aimed to uncover the processes that existed as parents interpreted and interacted in their situation within the environment of children's hospital care. This was an environment known to be controlled to some extent by professionals and in which parents were short or long term visitors to the environment.

The grounded theory approach to data collection, analysis and synthesis was initially created by two sociologists - Glaser and Strauss, in the 1960s, during their exploration of the subject of patients dying in hospitals. They documented the systematic methodological strategies used during this work (Glaser and Strauss, 1967) which had major impact on development of qualitative researchers across a range of professional groups including nurses. This novel approach to data collection and analysis challenged accepted wisdom from mainly positivist researchers at that time as it encouraged theory development from data. Researchers who favoured quantitative research methods often viewed qualitative research as being biased, subjective and anecdotal (Charmaz, 2006). However, there was little recognition that research questions for positivist studies limited the subject areas that could be explored. Glaser and Strauss's work demonstrated a whole new way of tackling complex questions that quantitative methodologists thought were unanswerable. In the late 1960s positivism remained the esteemed source of professional knowledge but Glaser and Strauss's work legitimised and added credibility to qualitative research as it provided a new methodological approach in its own right rather than simply acting as a precursor to quantitative study (Charmaz, 2006). Where previous qualitative research literature had focussed upon data collection in the field, the researcher's role in the setting and immersion in the data; Glaser and Strauss (1967) offered systematic guidance on the analysis and theory generation which is the hallmark of grounded theory.

In later years Glaser and Strauss adopted different stances on grounded theory with Strauss and Corbin (1990, 1998; Corbin and Strauss, 1990) developing a version of grounded theory which directed more verification than earlier comparative methods. This new version was not accepted by Glaser (1992)

who saw Strauss and Corbin's processes as forcing data into set categories which he felt was a complete departure from original notions of theory being allowed to emerge from data.

Later these two approaches to grounded theory became known as Glaserian or Straussian versions and Glaser, Strauss and Corbin are often referred to as first generation grounded theorists as subsequent iterations have emerged. In Glaserian grounded theory, researchers were advised that the phenomena of interest should arise during the research rather than begin with a research problem or any preconceptions. Glaser viewed review of the literature as potentially contaminating to data gathering although he did acknowledge the need to incorporate literature into developing concepts. In comparison, Strauss and Corbin proposed that researchers would identify a phenomena for study at the outset and conduct an initial literature review. Both versions of grounded theory discuss coding and categories and although there is some difference in preferences for terminology used there are also similarities between Glaser's 'theoretical' coding and the 'axial' coding identified by Strauss and Corbin. The main issue of contention between these authors lie in the verification issue. Where Strauss and Corbin advocated that there should be testing of working proposals against new data, Glaser argued that such hypotheses should not be verified at this stage but new data should be integrated into the emerging theory. The generating of the theory was another area for dispute as Glaser contended that provided researchers continuously engaged with data and that in-depth analysis occurred, the theory would emerge naturally. Strauss and Corbin, however, advocated that theory was constructed from axial coding. Differences also existed in that Strauss and Corbin viewed the theory as being co-constructed by researchers and participants whilst Glaser saw this as

emerging from data. The level of detail provided by Strauss and Corbin relating to procedures for grounded theory can be seen as being more prescriptive than Glaserian version. Some view this as a strength in the version particularly for novice researchers who may need this level of guidance whilst others see this as being a more formulaic approach and prefer the more flexible approach taken by Glaserian grounded theory.

A major criticism of these first generation grounded theorists has been their focus upon the methods rather than identification of the philosophical underpinnings of the methodology. This lack of an identified philosophical framework led to second generation theorists developing their own frameworks and producing further variations on grounded theory which has moved grounded theory design forwards (Charmaz, 2000; Charmaz, 2006; Clarke, 2005).

It is generally acknowledged that despite the variations in grounded theory approaches there are a set of methods that are required within the research design for the subsequent theory to be considered as 'grounded theory' (Bryant and Charmaz, 2007; Birks and Mills, 2011). The debate about relative merits of different versions of grounded theorists have continued over many years in the literature (Corbin, 1998; Boychuk et al, 2004; Heath and Cowley, 2004; Melia, 1996). 'Methodological slurring' within grounded theory has been discussed in the literature and Skodol-Wilson and Ambler-Hutchinson (1996) argue that such 'slurring' has arisen due to a range of misconceptions by researchers centred around generation erosion, premature closure and methodological transgression. A range of different types of grounded theory are now evident, for example, classic glaserian, straussian, constructivist and feminist grounded theory. The existence of such variations from the original methodology has

caused some writers (Bryant. 2009; Breckenridge et al, 2012) to question whether there is a point at which the extent of the revisions to the original methodology actually constitute a completely different methodology. Whilst such debates continue to surround the various evolved versions of grounded theory Breckenridge et al (2012) notes the challenge this poses for novice researchers in choosing which version of grounded theory to follow.

A different perspective on these debates is offered by Mills et al (2006) who appreciated that a dichotomy had emerged between researchers choosing between Glaser's approach and the later version of grounded theory espoused by Strauss and Corbin. Mills et al (2006) argue that grounded theory can be seen as a 'methodological spiral' starting with the original version from Glaser and Strauss and continuing forward on an evolutionary path. Grounded theorists can therefore adopt different positions on the spiral depending on their epistemological and ontological viewpoint. Charmaz's constructivist grounded theory is seen as being at the latter part of the spiral acknowledging that the researcher is ultimately the author of a reconstruction of the experience and its meaning.

Key elements of grounded theory are recognised as simultaneous data collection and analysis; development of codes and categories from the data; constant comparative data analysis; advancement of theory development throughout the stages of data collection and analysis (Glaser and Strauss 1967; Glaser 1978; Strauss, 1987). In addition, the final grounded theory to emerge from an exploration of a subject area needs to fit well with the data, be useful,

stand the test of time as well as being modifiable and explanatory (Glaser and Strauss 1967; Glaser, 1978, 1992).

Grounded theory acknowledges that no researcher can be “uncontaminated”, as human beings we live and work in the world we are researching and bring with us personal views and bias (Snape and Spencer 2003). The researcher’s own values, beliefs and knowledge are seen as inevitable within grounded theory methodology whilst interaction and flexibility is seen as adding value to the data rather than marring it (Hall and Callery, 2001). Mills et al (2006) comments that this methodological approach is epistemologically subjectivist acknowledging the nature of the relationship between the researcher and participants as they co-construct meaning. The important element is to identify and make transparent potential biases and take due cognisance of them in the interpretation and interaction with the participants and the data (Guba and Lincoln, 1989). The human interpretative aspects of knowing about the social world and the significance of the interviewer and interviewee’s own interpretations and understanding of the phenomenon under study is valued within this methodology (Alderson, 2001; Houghton et al, 2012). In this study it was the parents’ perspectives about what they had witnessed and experienced that were crucial and therefore the role of the researcher was to access and expose these perspectives through the data collection, analysis and reporting.

In this study the guidance offered by Charmaz (2006) was followed in the way that data collection in interviews occurred throughout the various stages. Open coding of each line or section of the transcript was relatively straightforward but then as more data was collected the tasks became more complex and the repeated return from coding to transcripts to interviews felt messy. Difficulties were encountered in drawing codes together to develop focused codes and

many weeks passed as connections were mulled over as I tried to understand why some aspects of the puzzle did not seem to fit together. My supervisors reminded me that at that this could signify that data was not saturated at that point thus the picture remained out of focus for me and further journeys round the cycle of data collection, analysis and comparison were needed. Construction of a substantive theory in this study required attention to the details of the processes recognised as the central tenets of the methodology. Having undergone these experiences with the data analysis there was a greater appreciation of the strengths of this methodology to explore and then explain basic social processes in new ways to appreciate how and why they occur in the way they do.

Charmaz (2006) noted that,

Glaser and Strauss shared a keen interest in studying fundamental social or social psychological processes within a social setting or a particular experience such as having a chronic illness. Thus, for them, a finished grounded theory explains the studied process in new theoretical terms, explicates the properties of the theoretical categories, and often demonstrates the causes and conditions under which the process emerges and varies, and delineates its consequences. (Charmaz 2006, p8)

Using this approach to create substantive theory also allows for the exploration of the theoretical categories generated within different settings both to refine and extend the theory. An example of this is where Glaser and Strauss used the categories relating to status passage generated in their study of dying to discover if the generic process existed across other substantive areas (Glaser and Strauss, 1971). Charmaz's (2006) approach acknowledges that any theoretical product will be an interpretive portrayal of the world under study, not an exact picture of it. This approach is one which reflected my own viewpoint at

the outset of this study and has become powerfully re-enforced as the study progressed.

Charmaz (2006) states that

Research participants' implicit meanings, experiential views – and researchers' finished grounded theories – are constructions of reality.(p10)

This statement fits in well with the ethos of this study whereby the parents' constructions of reality have been used to understand their interpretations and responses to these experiences thus enabling professionals to approach future interactions with greater insight.

I had worked in clinical practice for many years before undertaking any research and have, found myself at times moving between two opposing philosophical viewpoints:- the positivist and scientific approach to research and the qualitative, interpretative approach. My philosophical approach was not always clear to me until I reflected on the initial starting point of this study and had a moment of realisation that some of my difficulties in making decisions for the study's development had its roots in a basic personal struggle between the art and science of nursing. One side of this struggle was the search for the "right" answers or the "reality" of the phenomenon to be studied – this very positivist view of the world that existed for me may have been influenced by medical colleagues who favoured this approach to enquiry. Additionally, the nursing culture in which my career began was one which encouraged and valued an organised and tidy ward, one set of rules or procedures which were to be followed and an implicit apparent understanding of what was "good care" and what was "bad care". When undertaking a research study for my masters degree I utilised observational methods in a quasi-experimental approach which

was supervised by a nursing professor who valued positivist research methodology. The masters in health care research course I studied had evolved from a previous M.Med Sci programme which had been aimed at medical staff and delivered within the medical school. The influences of this research education alongside my previous nursing education and experience perhaps explains some of the tensions I experienced but had not really anticipated at the outset.

The opposing philosophical stance advocated by the qualitative and interpretative school of thought were equally important to me as my experiences as a nurse, manager, researcher and educationalist had taught me many times of the very different perspectives and interpretations people can have of the same situation. It is the richness and complexity of the qualitative data that drew me to this philosophical stance despite my fundamental desire to tidy and sort the rich tapestry into an orderly fashion. Analysis of the data and the generation of emergent themes that eventually have developed into a substantive theory has, it seems, satisfied my need to both unpick, unpack but also to create order.

Conclusion

This chapter has considered the aims of the research and justified the choice of the methodology with its underpinning philosophy. The influence of my background and experience have been considered and reflections have shown the personal research journey taken.

In the following chapter the study methods will be identified, in order to provide more detail of the way in which the research was conducted.

Chapter 4 Methods

Introduction

The purpose of this chapter is to detail constructivist grounded theory methods applied in this study. Ethical issues considered in undertaking the study are outlined at the outset as they are fundamental to the way in which the research was carried out. Strategies used to gather and analyse data will then be discussed including: sampling strategy; setting and recruitment of sample; quality assurance; data collection methods; stages of data analysis; memo development; theoretical sensitivity and theoretical saturation.

Ethical Considerations

Ethical approval to gain access to potential study participants was gained through the Local Research Ethics Committee (see Appendix 9) and the Head of Research and Development at the hospital site where recruitment occurred. In addition, the study was approved by the Ethical Approval Committee, Northumbria University, Caldicott approval was gained through the Caldicott Guardian of the Trust and full criminal record bureau clearance and occupational health clearance was also required before the study could proceed. The full approvals process was completed in April 2011.

In this study, as in any research carried out with patients, parents or carers of patients, it was essential that relevant ethical issues were considered and appropriate actions taken to protect potential participants. Current ethical research practices are based on the principles set out in the Declaration of Helsinki (World Medical Association, 2013) which aims to provide safeguards for the public. Participants have the right not to be harmed, the right of full disclosure, the right of self-determination and right to privacy, anonymity and confidentiality (International Conference of Harmonisation, 2002) and researchers have a responsibility to uphold these individual rights.

Information provision and consent

Potential participants need to be given clear and unambiguous information to enable them to make an informed decision to take part in research (Johnson and Long, 2006). Informed consent is central to ethical research, is an on-going process and consists of four key principles: disclosure (provision of relevant information), comprehension (understanding of the information), competence (participant's ability to make a rational decision) and voluntariness (no coercion) (Franklin et al, 2012). These principles have been adhered to within this study. Guidance about the content and standard of invitation letters, information sheets and consent forms was followed to ensure that the invitation letter (see Appendix 10), expression of interest form (see Appendix 11), information sheet (see Appendix 12) and consent form (see Appendix 13) fitted the requirements and were ethically sound.

Johnson and Long (2006) acknowledge that whilst researchers must provide honest information about potential risks and benefits for participants, a balance needs to be achieved so that studies do not appear more risky than is the reality. When constructing information sheets and invitation letters the challenges became evident of striking the right balance between risk and benefit as well as avoiding using persuasive tones within the information. In this study the plan was to conduct a series of interviews with each participant but it was not known how many interviews with each participant would be required to reach data saturation. Invitation letters, therefore, needed to state the expected number of interviews a participant may be involved in, although this number of interviews might not be necessary for everyone and all participants would have the option to withdraw at any point. There was a danger that potential participants would decline involvement due to the time commitment or concerns that they would not have sufficient to contribute to warrant being interviewed several times. Protective processes of the ethical approval system ensure that participants are recruited without direct approaches being made by the researcher to avoid any undue pressure or leverage being used to gain consent. However, the use of other parties to inform and invite participants to the study can potentially adversely affect numbers recruited perhaps through less enthusiastic and active presentation of the study.

At the outset of the interviews there was the opportunity for participants' questions to be answered to clarify the purpose of the study. It was re-iterated to participants that they could withdraw consent at any time without it affecting their position. The fact that I was not an employee of the Trust at the point of interviewing was helpful in reassuring parents of my position as an outsider to the organisation we were talking about.

Maintaining confidentiality

The ethical approval processes seek reassurance that the researcher is aware of the need for confidentiality and will work within the governance arrangements of their organisation to maintain the participants' confidentiality. Maintaining anonymity and confidentiality within interpretive research is critically important as the nature of this type of research involves sharing personal experiences, thoughts or feelings. Anonymity and confidentiality for participants in this study was protected by the use of pseudonyms and the removal of detail that might reveal a participant's identity. All data was securely stored with password protected access to data limited to the research team. Participants were made aware of the potential outputs of the study and the fact that some direct quotes may be used although they would be anonymised.

Participants were given the opportunity to withdraw any information that they had shared during the interview that they did not want to be part of the study. This was achieved by explaining this at the outset of the interview and then re-visiting this at the end of the interview ensuring that the participants were happy for me to use the information they had disclosed. During the study there were no situations where participants asked for any information they had provided to be discarded.

Careful wording and consideration was given to the elements of the information sheet which explained that whilst confidentiality was assured there were some situations where this may not be possible, for example, in cases where parents

may divulge information where there was a breach of professional code or neglect warranting formal investigation or complaint. Such situations were viewed as unlikely but needed to be acknowledged to participants and the researcher's responses planned. These scenarios were discussed with supervisors and principles of the researcher responses were devised and discussed with the research ethics panel. In the interviews there were no situations that raised such major issues although this is not to say that parents did not broach difficult and negative reports of service provision.

Distress

It was clear that in the interviews there was potential for parents to become distressed as they recounted their experiences with their child. It was appreciated that this may occur even when parents felt that they were very able and happy to talk about these events and feelings. The need to anticipate, recognise and manage such situations sensitively was considered in the conduct of the interviews. Strategies to support distressed participants during and after interviews were detailed in the ethical approval submissions, recognising the importance to do no harm to participants. My plan was to openly discuss with parents the potential for them becoming distressed as they recounted their experiences. Acknowledging that this might be a difficult subject for them to talk about and that I anticipated they may become upset was intended to make them feel comfortable if this occurred. Options to pause or stop interviews at any point were explained. It was anticipated that my own nursing experience would enable me to recognise early any signs of distress and be able to offer appropriate comfort and emotional support should

interviews need to be paused or stopped. I expected that this would involve taking a break from the interview and perhaps changing the subject until they had regained composure or through offering support and understanding of the matter that prompted the emotional reaction at that point. If the individual's distress continued and required additional intervention the plan was to seek further support for the parent, with their permission, through their clinical team.

On a few occasions during the interviews parents did become visibly upset as they recounted certain aspects of their child's care and needed to take a little time before they could continue to tell their story. On most occasions they quickly recovered their stride and acknowledged that they knew that they would be upset at that part of the story. They usually assured me they were fine and signalled to me to leave the tape on if I reached to pause the tape. At other times the emotions seemed to appear suddenly and unexpectedly as they tried to recount the experience. It seemed as if they were back in the moment of the event and the emotions of that time came flooding back. In such situations it was necessary to stop recording, although all parents in this position chose to continue with the interviews after a short break.

Sampling Strategy

Initial sampling in grounded theory studies is normally purposive in nature and facilitates the recruitment of participants with experiences relevant to the aims of the study (Birks and Mills, 2011). This provides a starting point for data collection and enables the exploration to begin. Theoretical sampling, a key component of grounded theory, is adopted once the constant comparative analysis of the data is underway (Mays and Pope, 2000; Birks and Mills, 2011;

Holloway and Todres, 2006). Coyne (1997) has previously noted a level of ambiguity within the literature in distinguishing between purposive and theoretical sampling and more recently, Charmaz (2006) has argued that such ambiguity arises from researchers' preconceptions regarding sampling. She emphasises that it is sampling to develop emerging theoretical categories that makes theoretical sampling distinct from other qualitative sampling approaches.

Emerging concepts of significance for the developing theory are allowed to guide the study's direction through the selection of specific participants for interview, to further define the developing categories. This approach, whereby the emerging theory controls the future direction of the study (Alvesson and Sköldberg, 2009) enables the development of the categories to a point where data saturation is achieved. In other interpretive research methodologies decisions about the sample of the population are normally pre-determined but this is not the case in grounded theory. The nature of theoretical sampling means that the direction of the sampling is to some extent unknown at the outset of the study. Although this can be viewed as a strength of the methodology and reflects the exploratory nature of the approach this does require the researcher to outline a degree of flexibility within applications for ethical approval to accommodate potential changes as the study progresses (Duffy, Ferguson and Watson, 2004).

It is generally accepted that the number of participants included in a sample for qualitative research may be small, that is, ranging from two or three participants to up to fifty (Parahoo, 2006 ; Ritchie and Lewis, 2003) especially when compared to quantitative research studies where large representative samples

are highly valued. The difference in these expectations around both size and composition of the sample is accounted for by the purposes of the research approaches. In qualitative research the intention is to gather rich, in-depth data to address the research questions of the study and samples are non representative in nature as they are not aiming to generalise results to wide populations. According to Sandelowski (1995) the sample size in qualitative studies should neither be too large or too small: a sample that is too large may inhibit in-depth analysis and too small may hamper attempts to provide rich appreciation of the experiences explored. Sandelowski (1995) considers the sample size to be a matter of judgement for the researcher in terms of adequacy in addressing the research questions and therefore does not provide an ideal numerical value for samples.

Estimating the sample size in a qualitative research study at the outset may not be helpful given that it is the concurrent data collection and preliminary analysis that informs the appropriateness of the final sample size. In this study it was recognised that the predicted minimum and maximum size of the sample needed to be flexible as theoretical saturation of the categories was the real guide to the completion of data collection.

Setting and recruitment of sample

This research study was undertaken between 2011 and 2013 within the Children's Services of a large NHS Foundation Trust in the North Of England. Parents from eleven wards and departments were invited to participate, these wards/departments included: paediatric medical and surgical wards;

oncology/haematology wards, medical assessment ward, burns and plastic surgery ward and paediatric intensive care. The services provided by the Trust encompass emergency, planned, ambulatory and community paediatric care as well as an extensive range of specialist services. Care is offered within the departments for babies, children and young people and the Trust also houses a comprehensive range of adult clinical services. During the study the Trust was undergoing many changes which included building and organisational change although existing services were maintained throughout this period.

In this study parents of children who had received hospital care within the Children's Services Directorate of a NHS Foundation Trust were invited to participate. Parents were recruited from Initially broad inclusion and exclusion criteria were used to determine the starting point for the recruitment of participants (purposive sampling) although a more focused approach to selection of participants for inclusion was used later (theoretical sampling) determined by the emerging concepts from the data. Below are the criteria which were used in initial recruitment of participants:

Inclusion Criteria - Parents of children (12 years and under) who had been admitted for hospital care to the Children's Services of a NHS Trust.

Exclusion criteria- Participants where the clinical team considered it to be inappropriate to approach the family e.g. in situations where bad news had recently been received; where there was a child protection issue or where the child was a 'looked after' child.

These broad, inclusive criteria meant that any parent (except those within the exclusion criteria) whose child had been hospitalised was seen as a legitimate

informant whose views could be helpful to the researcher in developing a full understanding of the experience.

The sample

In this study the sample recruited consisted of parents ($n=9$) of 8 children (aged 12 years and under) who had experience of hospital care within the children's service of one acute hospital Trust (see Appendix 14 for further details of the participants). The parents included some fathers ($n=3$) and mothers ($n=6$) and within these numbers were two couples - one couple were interviewed together and one couple separately. The range of the parents' experiences of their children being in hospital were diverse and included babies and children; planned and unplanned hospital admissions; relatively minor illnesses to life threatening illness/injury; chronic illnesses requiring on-going home care or regular hospital care and congenital problems.

In grounded theory, initial sampling decisions are based on accessing participants who have knowledge and information about the area under study (Charmaz, 2006) and the wide inclusion criteria set out for this research reflected this notion. The number of participants initially proposed for this study were to include a minimum of 6 and maximum of 12 participants to be recruited to the study. The plan was to interview each participant up to four times if they were willing to continue to take part and if it was felt appropriate to further explore with them subsequent experiences or reflections on care.

As this was a study concerned with parents' perceptions of their children's hospital care experiences, it was decided that the age of their child at the time of the experience should be 12 years or below. The rationale for this age limit was to ensure that the participants were the individuals who would have main responsibility for decisions to access health care services when their child was ill or injured (Neill, 2010). In addition, the focus was on hospital care of children rather than teenagers and young adults where the emotional, psycho-social and physical care needs often differ considerably (RCN, 2011; DH 2004b). Parents of children in this younger age group (0-12) would also be most influential in decisions about when and where to take their child when hospital care was required and would also be most likely to be the individuals asked to evaluate the health care services received.

There was a need to balance breadth and diversity of the sample with increasing focus and interviewing participants on more than one occasion was expected to provide a rich source of data to explore the emergent themes and provide focus. The interviews were planned to take place over one year as this enabled exploration of the notion that judgements of quality of care may change over time or be modified in the light of new experiences, knowledge or through exposure to other people's opinions (Williams et al 1998; Edwards et al 2004). Findings from studies with adult patients have shown that levels of satisfaction of care can alter positively as time moves forward (Williams et al 1998; Edwards et al 2004; Staniszewska and Henderson 2005) and it was important in this study to examine whether this was similar or different within parental experiences and reporting.

The first approach to recruit parents to the study was to come from nurses so it was important that they were fully informed and in agreement with the process.

In addition to informal and individual discussions of the study with nursing staff within the unit a formal presentation of the study was made at the Trust's Children's Services' Ward Manager's meeting. Ward Managers were given opportunity to discuss the study and to have their questions answered. Once agreement was reached, Ward Managers were given recruitment/ information packs to distribute to parents fitting the study's inclusion criteria. For practical reasons Ward Managers decided the date on which recruitment packs were given out on their individual ward/departments (n 11). The wards and departments included were: paediatric medical and surgical wards; oncology/haematology wards, medical assessment ward, burns and plastic surgery ward and intensive care. Whilst the out-patient area was the only area specifically excluded from the study, parents did discuss these out-patient experiences within interviews. Critical care areas were provided with recruitment packs although it seemed less likely that parents would be recruited from these units due to discharge usually involving transfer to the wards or hospitals rather than direct to home. (Again, although ultimately no parents were actually recruited direct from critical care areas, parents with previous critical care experiences spoke of these experiences within interviews).

Once recruitment began all parents of children being discharged from the ward would receive a recruitment pack from their nurse at the point where the nurse discussed final discharge arrangements with parents. Nurses were asked to provide a brief explanation of the study when they gave parents the packs. The pack contained: an 'invitation to participate' letter, an information sheet, an "expression of interest" form and a stamped addressed envelope. This process continued until all of the ward's supply of recruitment packs were distributed. Inclusion criteria were deliberately broad so as not to exclude potential

participants and with the aim of recruiting a diverse range of participants. Ward Managers appeared to be keen for their areas to be involved in the study and were confident that many parents would participate.

Initial concerns were that having distributed the recruitment packs I might find myself inundated by parents wanting to take part in the study which would exceed maximum recruitment numbers. However, after several weeks patiently checking my post tray I realised that rather than an over-recruitment problem I was facing a zero recruitment issue. Following discussion with my supervisor I began to appreciate the potential barriers to recruitment which I had not fully accounted for in my planning. It was apparent an additional recruitment strategy was needed. A further presentation and discussion took place with Ward Managers' at their monthly meeting to re-iterate study information and to remind them to distribute the recruitment/information packs. There was a need for dialogue at this stage to determine any blocks to recruitment i.e. was the problem in getting information to parents or were parents just not wanting to take part. The Ward Managers reassured me that they had been distributing packs and that all parents they had talked to had intended to participate and would return completed forms once at home. More packs were given out and I felt reassured that participants would start replying very soon.

Once an 'expression of interest' form was received I contacted the parents to organise a convenient time and place to interview them. Although responses remained slow, interviews were soon able to commence with the first two participants being recruited from ward areas. Constant comparative analysis of data collected from these interviews revealed some preliminary concepts requiring further exploration. Theoretical sampling is the strategy adopted, after initial data analysis has occurred, to seek out subsequent relevant data sources

to enable greater understanding of these preliminary emerging concepts (Charmaz, 2006). Gathering of data is then focused on enhancing and refining the properties of these concepts until robust categories are developed that can form the basis of the grounded theory (Charmaz, 2006). The first parents that were interviewed had experience of acute hospital care with their children for relatively common childhood illnesses. Initial coding of these first interviews revealed concepts that needed deeper exploration to ensure a fuller understanding of the parents' perspectives was achieved. The study's design incorporated a series of interviews with participants and this allowed these early concepts to be re-explored with the same group of parents. Interviewing the parents on several occasions presented a rich opportunity to explore concepts with them as they were developing; seeking clarification and expansion on previous information provided to fully understand their experiences. Theoretical sampling within the data gathering processes effectively enabled deeper 'mining' of the data to occur which supported the on-going dialogue with parents as the grounded theory was constructed. Emergent findings also guided recruitment towards parents of children with longer term and more serious illnesses to enable further development of the concepts and emergent theory from the exploration of potentially different parental perspectives. Engaging with the specialist nurses to identify and invite parents with these experiences proved successful and a diverse sample was obtained. Whilst reliance on insider "gatekeepers" to recruit participants on my behalf was challenging as a researcher keen to progress the data collection, it did allow participants to freely take part or refrain from taking part without feeling coerced into it.

It quickly became evident that when parents were interviewed about the quality of the care of their child in hospital, they rarely spoke about one experience in

isolation, at one point in the child's life or only one of their children. Most parents had some experience of both emergency and planned hospital experiences which they drew upon in their interviews and their stories and evaluations of care quality usually also reflected personal expectations from their own experiences as patients. However, in the absence of such experiences they relied upon comparisons with a whole range of other life experiences and existing knowledge and expectations

Quality Assurance

Quality within a research study is underpinned by researchers working consistently within the philosophical assumptions and traditions of the chosen research paradigm and approach (Lincoln and Guba, 2000). Application of systematic processes to data gathering and analysis, and transparency in procedures followed are also necessary to confirm reliability of the methods and trustworthiness of the findings (Koch and Harrington, 1998; Lincoln and Guba, 2000 ; Silverman, 2005). There has been much controversy about the most suitable terminology to be used when determining quality in qualitative research. Association of the terms reliability and validity with quantitative research has caused them to be rejected by some qualitative researchers whilst others have argued that such terms are appropriate for both quantitative and qualitative research (Whittemore et al, 2001). Despite these debates there is a general consensus that trustworthiness is the key element that needs to be established within high quality qualitative research. Lincoln and Guba (1985) initially identified four criteria for trustworthiness in qualitative studies: credibility, dependability, confirmability and transferability. Later, authenticity was added to

these criteria (Guba and Lincoln, 1994). These criteria to some extent offer parallels to the quantitative researcher's quest for reliability and validity.

Credibility is viewed as being centrally important and relates not only to confidence in the truth of the presented data but also in the interpretation of the data. To achieve credibility the researcher needs to be rigorous in applying the methods of the chosen methodology but is also required to make this explicit to those reading the research. Creswell and Miller (2000) suggest that a range of strategies are commonly used by researchers to enhance validity or credibility within qualitative research which include prolonged engagement in the field, thick rich description, member checking, researcher reflexivity and development of an audit trail. They propose that such strategies reflect both the researcher's lens and paradigm assumptions of the approach undertaken in the study and suggest that most researchers cite one or more strategy as evidence of the credibility of their research.

Strategies to enhance credibility in this study have included the use of a reflexive journal and recording of contemporaneous field notes, both of which provided an audit trail of the decisions to support the completion and presentation of the study. The audit trail provides a record of decisions taken in the development and progress of the study. It is both a way of demonstrating transparency, thus allowing the reader to judge the credibility of the research and also a methodological tool to support the researcher in personal critiquing and developing the study (Lincoln and Guba, 2000; Anfara and Mertz 2006). The journal entries, field notes, memoing and diagramming within this study were used to promote discussion and challenge assumptions and interpretations within supervisory meetings during the constant comparative data and theory development stages. Audio-recording, verbatim transcription

and accuracy checking of all transcripts were carried out to further ensure quality within the processes. Charmaz (2006, p.18) suggests that a grounded theory study's quality and credibility begins with the gathering of rich, substantial data. In this study, credibility was enhanced by the diverse experiences within the sample and their willingness to share their experiences and reflections during the interviews. Creswell and Miller (2000, p. 127) referred to 'prolonged engagement in the field' and the series of interviews used in this study enhanced the relationship between researcher and participants over an extended time period supporting fuller exploration and deeper discussion of the topics and the opportunity through theoretical sampling to further mine the data for confirmation of potential understanding and interpretations. Care was taken to build rapport with the participants and the study's design further facilitated this as trusting relationships developed through repeated interactions. Rapport building has been acknowledged as essential to participants in enabling them to share their personal, emotional experiences and perspectives with the researcher at a level that facilitates the discovery of aspects that may initially be seen as regular or mundane to the participants (Charmaz, 2006). Throughout the study the reviewing of transcripts, critical reflection and discussions with supervisors and peers also supported improvements in my ability to sensitively gather quality, in-depth data.

The findings chapters of this thesis provide rich verbatim accounts providing context and explanation and these accounts allow the reader to determine for themselves the extent of the fit between the parents' accounts, the coding and the emergent theory (Creswell and Miller, 2000). In this study there have been on-going opportunities to check out with parents the developing concepts as the emergent theory was constructed rather than member checking on a single

occasion. Checking interpretations of the data is also built in to grounded theory through the use of constant comparative analysis, memoing and theoretical sampling processes (Elliott and Lazenbatt, 2005). In this study, emphasis was placed on minimising researcher bias through the use of a reflexive journal, memoing and critical discussions with supervisors and peers. Aspects of bias are re-visited within the thesis as the work continues. Steps taken to ensure the participants' perspective was heard within the study and not the researcher's own perspective demonstrates a level of confirmability within the study. Throughout the conduct of this study close attention has been paid to assuring quality within the research processes to protect the credibility and integrity of the work and the final constructed grounded theory.

Authenticity refers to the fair representation of participants' realities (Guba and Lincoln, 1994) and this is demonstrated in this study by the faithfulness of the depiction of the parents' perspectives within the thesis, the use of the parents' voice within the findings chapters and the in-vivo coding incorporated within the emergent theory. Achievement of authenticity is thought to be achieved when the reader develops a heightened appreciation of the participants' perspective.

Transferability refers to the extent to which findings are applicable to other settings and it is the researcher's role to ensure that sufficient detail is provided about the context of the findings to allow the reader to make such judgements (Koch, 2006; Anfara and Mertz, 2006). It is not possible to show external validity of the findings beyond the context in which they emerged but the provision of thick description within the study enables others to decide if the findings may be transferable.

Data Collection: Interviews

In this study it was important to enable parents to articulate their own narratives and reflect on the meanings and personal interpretations of their hospital experiences. By exploring these personal perspectives, over time, it was anticipated that the way that parents' judged the quality of care provision would emerge. It was for these reasons that a series of in-depth unstructured interviews were undertaken with parents following their child's hospitalisation. Interviews are commonly used as a data collection tool by qualitative researchers (Ryan et al, 2009; Legard, Keegan and Ward, 2003; Sandelowski, 2002) as they offer opportunity for participants to share their life experiences, personal beliefs and values with regard to specific research questions or phenomena of interest (Lambert and Loiselle, 2008). Research interviews have previously been described as conversations (Chenitz and Swanson, 1986); guided conversations (Rubin and Rubin, 1995) and conversations with a purpose (Burgess, 1984). However, Ryan et al (2009) proposes that interviews are much more than a social interaction, viewing them as a process with distinct purpose constructed to elicit meaning about particular situations. Similarly, Price (2002) argues that the information sharing that takes place in an interview occurs in a different way to ordinary conversations: researchers guide interviews and use their skills to uncover critical, information relevant to research questions (Fontana and Frey, 2000). The way interviewers can move the dialogue in different directions, explore "hunches" and examine earlier events and feelings distinguishes interview inter-actions (Charmaz, 2006). It is likely that skilled interviewers can make an interview seem like an informal

conversation, in reality, it is more purposeful and in this study my aim was to manage the interviews to achieve this appearance.

Using unstructured interviews allows participants to provide a narrative that prioritises and emphasises their interpretations of experiences, unimpeded by interviewer questions. Interviewers seek to understand participants' perspectives acknowledging their prime position to shed light on the topic under study (Charmaz, 2006; Seidman, 2103). Strengths of unstructured interviews lie in the flexibility to alter the direction of discussions; potential gather rich data uncovering topics difficult to access and opportunity to clarify or explore specific issues as they arise (Robson, 2002). In addition, there may be cathartic benefit for participants as they reflect and voice their views (Edwards and Talbot, 1999). However, such interviews can be costly and time consuming to undertake and may produce large amounts of data that may be irrelevant to the study's focus (Edwards and Talbot, 1999; Robson, 2002).

Sequential interviews are useful where a researcher aims to capture evolving experience or follow changes in participant's experiences, health or expectations (Tod, 2006). Opportunity to return to participants several times can also enhance development of trust between researcher and participants enabling collection of in-depth, high quality data (Birks and Mills, 2011; Charmaz, 2006). Further benefits of interviewing participants more than once are the potential to use theoretical sampling to enhance mining of the data, returning to participants for further exploration and clarification of issues. In this study, although initial interviews were unstructured subsequent interviews

became increasingly focussed to enable specific concepts to be examined. Grounded theory requires data collection and analysis to occur simultaneously and undertaking a series of interviews enhances the continuous flow of concepts from analysis to be fed back into the next set of interviews as the emerging theory develops.

The aims of this research required exploration over time of the parents' judgements of care and therefore undertaking a series of interviews fitted well with this goal. In this study 22 in-depth interviews were conducted between September 2011 and May 2013 (see Table 2). An overview of the parents within the sample is provided in Appendix 14. Each interview lasted between 50 and 90 minutes and was tape recorded and transcribed. Field notes were also recorded after each interview to capture the non-verbal aspects of the interview and to provide detail of initial impressions and emphasis given by participants to particular topics. Reflective researcher notes were also recorded. It should be noted that within the thesis the term 'children' is used for brevity although the study includes parents of babies and children up to twelve years of age. The participants' accounts of events are given from their personal perspective and it is acknowledged that this is their memory of these experiences which may not necessarily be an entirely accurate or comprehensive record. It is necessary, therefore, to acknowledge that other people and professionals involved at the time of various events or exchanges may have given an alternative view to the parents but this study has chosen to focus on the parents' personal perspective.

Table 2. Chronology of parents' interviews

Parents and their key hospital experiences	Interviews conducted with each parent				
	1	2	3	4	5
Angela Acute minor illness; life threatening illness; emergency care; surgical; orthopaedic care.	√ 4/9/11	√ 3/12/11	√ 23/4/12	√ 11/9/ 12	√ 21/12/12
Graham - Acute minor illness; life threatening illness; emergency care; surgical; orthopaedic care.	√ 23/4/12	√ 11/9/12	√ 21/12/12		
Norma chronic illness requiring weekly day care	√ 30/9/11	√ 30/3/12	√ 7/5/13		
Gina neonatal care; surgical care; ophthalmology; complex care needs.	√ 2/12/11	√ 23/3/12	√ 23/11/12		
David - neonatal care; surgical care; ophthalmology; complex care needs.	√ 2/12/11				
Mary acute minor illness	√ 9/9/11				
Helen life -threatening/changing illness; Intensive care; surgical; emergency care.	√ 30/1/13	√ 12/4/13			
Brian emergency short stay acute care	√ 13/3/12	√ 4/3/13			
Wendy newly diagnosed child with chronic illness. Short stay acute care	√ 16/9/11	√ 19/12/11			

The parents who were interviewed on three or more occasions were parents who had substantial and on-going experiences of hospital care with their child or children and were also willing to be interviewed on several occasions. At

each of these interviews there were new episodes of care or further discussion of their many previous experiences to explore. It was apparent that for some parents one or two in-depth interviews provided sufficient time for them to fully explain their experiences and to allow exploration of particular issues with them in some depth. A second or third interview was therefore not arranged where the purpose of the series of interviews was already achieved or where the researcher sensed that to request further interviews may not be appropriate due to individual circumstances or where the parents appeared to have already made their full contribution to the study within these interviews. The balance between collection of data and being sensitive to the intrusion on the participants time and goodwill was an important consideration in managing the series of interviews. Some parents who were only interviewed on one occasion did not respond to requests for further interviews but may have been able to further contribute to the study's findings had they taken part in subsequent interviews.

In this study the majority of interviews were carried out in the parents' own homes, during the day, when the children were at school. Consent forms were signed by all participants once verbal and written information about the study had been provided; any questions had been answered; reassurances about withdrawal were re-iterated; anonymity and confidentiality was assured. Initially, a maximum of four interviews was envisaged with each participant to enable capture of changing perspectives over time. However, it became evident that the number of interviews required to produce sufficient data varied in accordance with the participants experiences, the on-going nature of their experiences and the number of episodes of hospital care.

Managing the interviews

Whilst interviewing offers opportunity to gather rich in-depth information from participants to develop theory explaining processes and relationships within social scenarios (Tod, 2006), the extent to which this potential is fulfilled is dependent on the skills of both researcher and participant. Researchers need to enable participants to share their experiences and participants need to be able to articulate their own perspective or reality (Holstein and Gubrium 1995; Gubrium and Holstein, 2001; Patton 2002; Lambert and Loiselle, 2008). Charmaz (2006) states that the grounded theory interviewer is:-

there to listen, to observe with sensitivity, and to encourage the person to respond. (2006, p25)

This statement gives recognition to the interviewee as expert within grounded theory research and the interviewer's role as facilitator in making the participant's voice heard. It is acknowledged that the power balance in interviews can be an issue for researchers (Price, 2002) and despite researchers approaching interviews believing that the participant is the expert, this may not be how the participant initially feels in the interview situation. The reality is that the interviewer has already set the agenda for the research interview and is in a stronger position to control direction and duration of the interaction than the interviewee. It is from this position that interviewers have to begin to work to address power imbalances to enable participants to feel able to engage fully. Critical to addressing these issues is development of a good rapport and trusting relationship with participants so that they can speak openly

about their experiences to gathering rich insights into participants' perspectives so that researchers can see the world as they see it (Legard et al, 2003; Thompson, 2000; Tod, 2006; Charmaz, 2006). Participants need to feel they are in a safe, non-judgemental environment to share details of their experiences, their interpretations of experiences and their own feelings (Thompson, 2000; Tod, 2006; Charmaz, 2006). Demonstration of the right demeanour, attitude and interest by the researcher is important and may impact on the quality of the data (Legard et al, 2003). In the interviews for this study I ensured that my manner, verbal and non-verbal behaviours and non-judgemental approach towards participants demonstrated respect for them and a genuine desire to learn about their experiences from their perspectives.

Charmaz (2006) suggests that researchers should reveal some of themselves to the interviewee but be aware of the possible impact of this information on the interviewee this can pose a dilemma for researchers in how to present themselves. In this study invitation letters (Appendix 2) identified me as a Principal Lecturer undertaking a research study regarding the quality of children's care. This presented me as an educationalist and research student external to the hospital rather than a children's nurse. However, prior to the start of interviews I did explain my previous roles in children's nursing and current role teaching children's nursing students. This information, I believed, enabled parents to talk about their experiences knowing that I would understand some of the context to their experiences. My role as an educator may have enhanced my credibility as parents seemed to view interviews as an opportunity to voice their opinions to someone who could influence future practice.

At the beginning of the interviews time was spent on introductions and developing a rapport with the parents. The opening question at each first interview was – “Can you tell me about your experiences when *child’s name* was in hospital?” This enabled parents to begin to tell their stories in their own way with further questions being used later to clarify points and to check the meaning and interpretation of the experiences they described. Allowing participants to speak uninterrupted is acknowledged as appropriate by Charmaz (2006) as interviewers need to understand the interviewee's perspective and show sensitivity as they divulge their personal story. The way that parents told their stories was interesting as they tended to relive the events for me and included much detail to emphasise the normality of their day leading up to the event or experience with their child and the emotional effects of this. Clearly for some the impact of the experience was life-changing and the shock to them was recalled vividly. Opportunity for more focussed questions about parents’ judgements of quality of care were added to subsequent interviews to follow up on their early interview responses and topics emerging from initial coding which required further exploration and clarification.

The interviewer's role is to collect rich in-depth data from the interviewee but this is a sensitive interaction which needs to be carefully facilitated by the interviewer (Tod, 2006). Gathering such data involves a degree of probing into participant’s private thoughts (Gordon 1998; MacDougal 2000) and this needs to be carried out ethically and sensitively. Charmaz (2006) advises that interviewers should “read the mood” of the interview so that probing questions are used to just the right extent to uncover important details without being too intrusive and leaving the interviewee feeling they have shared more information than they would have wanted. Unstructured interviews within grounded theory

offer good opportunity to capture vivid pictures from participants' perspectives but the free exchanges between interviewer and interviewee can place greater demands on interviewers to avoid biasing the responses. Interviewing techniques employed ought to encourage full answers to questions without influencing actual responses (Legard et al, 2003). To minimise potential bias, questions need to be posed in a neutral manner; leading questions and the appearance of approval or disapproval to responses avoided (Mack et al, 2005). Charmaz (2006) acknowledges the inherent challenges for the grounded theory researcher to avoid imposing personal pre-conceived concepts and perspectives upon the participant's own reality through their questions and suggests a constant reflexive approach to counteract biasing the data. In this study, constant re-visiting of data enabled repeated reflection on the effectiveness and openness of my questions and this scrutiny minimised personal bias in data gathering and further assured the trustworthiness of the findings.

Questioning techniques that were useful in the interviews included laddering questions (Price, 2002) and probing techniques as described by Russell Bernard (2000). Laddering questions (Price, 2002) is a technique whereby initial questions used are least invasive (actions and behaviour questions) and proceed to more probing, deeper questions (knowledge and then philosophical questions) if respondents signal their readiness. The technique is based on the premise that this is a social convention that is already operating within social discourse. These techniques fit well with the series of interviews conducted in this study as there were opportunities to use different levels of inquiry as relationships between participant and researcher developed.

Following Russell Bernard's (2000) approach, further techniques that were used in this study to elicit information from participants involved the use of silence to encourage the participant to continue to talk (silent probe); repeating the participant's last point to invite further elaboration (echo probe); general verbal signals of interest- saying "yes, ok" or "yes, I see" (uh-huh probe); demonstration and explicit questions designed to expand on initial response (tell me more). In grounded theory, Melia (2000) has suggested that verbal memo-ing is useful whereby emerging ideas from initial analysis can be tested out with participants to further illuminate issues from different viewpoints. This strategy was used with parents to check the interpretation of the data analysis and to co-construct meaning within emerging categories. In addition, brief examples of other parents' experiences (appropriately anonymised) were put forward to explore whether they had similar or different experiences themselves; felt the same way or differently about the experiences and whether the emerging categories from the data reflected their own interpretations.

Whilst the use of laddered and probing questioning and verbal memo-ing techniques may elicit more in-depth data, ethically the researcher needs to be judicious in their use. Charmaz (2006) advises researchers to be guided by participants' comfort rather than the desire to obtain '*juicy data*' (p30); listen closely for the right time to probe further and try to understand the experience and its meaning from the individual's viewpoint. The exploration of complaining or feeding back about concerns about care were examples of areas where careful probing was needed. Some parents' looked perplexed and a little uncomfortable when these topics were raised with them and this alerted me to their sensitivities in this area. Refinement of the way that I explored this area in

subsequent interviews enabled parents to talk more freely about this subject and revealed important information about the way that parents' viewed their role as protectors of their child (this subsequently formed part of the core category - "on guard").

Data analysis

In grounded theory, differences exist in data analysis processes and terminology used dependent on the approach taken, for example, classic Glaserian, Straussian or Charmaz's constructivist grounded theory (see Table 3). Critical discussion of these various types of grounded theory can be found in chapter 3 of this thesis and a rationale provided for the constructivist grounded theory approach adopted in this study.

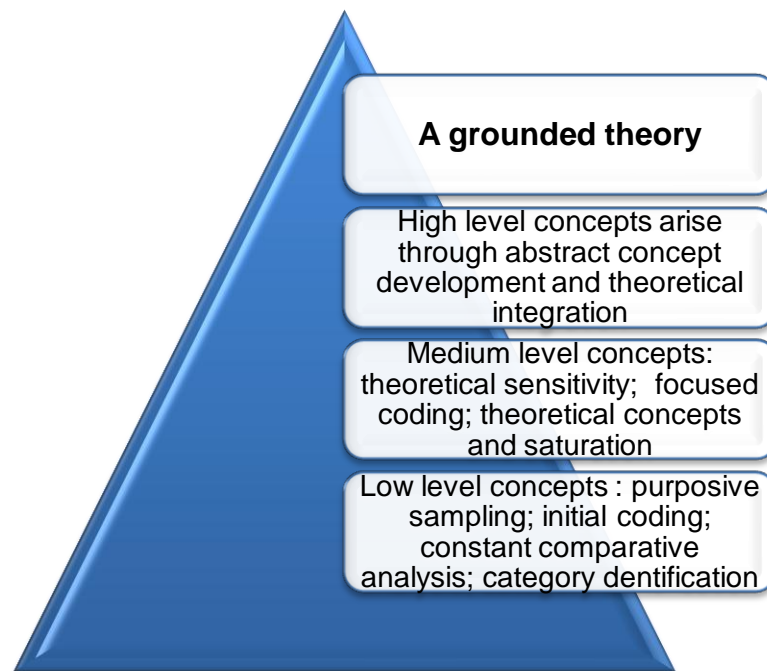
Table 3. Grounded theory - concept terminology (adapted from Birks and Mills, 2011)

Concepts					
	Codes	Categories	Properties and dimensions	Core category	Methods of data abstraction
Glaser and Strauss (1967)	Coding incidents	Categories	Properties	Systematic substantive theory	Common sociological perspective
Strauss and Corbin (1998)	Coding paradigms: conditions, actions/interactions and consequences. open, axial and selective coding.	Categories and sub-categories	Properties, dimensions and coding for process	Central category	Storyline and the conditional/ consequential matrix
Charmaz (2006)	Initial, focused and theoretical coding	Categories	Properties	Theoretical concepts	Theoretical codes

Common to all grounded theory approaches is the constant comparative data analysis which differentiates it from other interpretive approaches (Birks and Mills, 2011). This method requires data collection and analysis to occur

simultaneously in an iterative way (Charmaz, 2006; Lathlean, 2006; Ritchie and Lewis, 2003) with coded data continuously being compared with new data and each informing the other. Therefore, data analysis begins early and guides subsequent data collection (Lathlean 2006) with the researcher moving back and forth between data collected and further queries for future exploration. Analysis is intimately linked to data collection, guides theoretical sampling and involves both cognitive processes and the application of structured techniques (Birks and Mills, 2011). Ritchie et al (2003) comments that there are two common processes underlying all qualitative data analysis, which is to manage data by reduce and distilling the “essence” from it and these processes apply regardless of the approach taken. Whilst this provides a basic view of the similarities of qualitative data analysis approaches, Charmaz (2006) identifies coding in grounded theory as requiring more than the sifting, sorting and synthesising process used in other qualitative methods. In constructivist grounded theory the difference primarily lies in the bringing together of concepts from the coding that have been deliberately left open to possibility and are then united through constant comparative data analysis (Charmaz, 2006). The researcher is required to advance low level concepts produced from initial open coding of data to the higher more abstract level concepts that enable the construction of a grounded theory (see Figure 2). Theoretical sensitivity and memo writing are recognised as being critical in advancing this process (see Figure 2) and as conceptual links and connections are uncovered more abstract concepts emerge thus raising the theoretical concepts and ultimately widening the application of the final constructed theory (Böhm, 2004).

Figure 2. Grounded theory methods and conceptual development (adapted from Birks and Mills, 2011)



In this study, following Charmaz's (2006) guidance, the constant comparative analysis method was adopted with initial, focussed and theoretical coding being undertaken. To assist in the management of data coding the qualitative software programme NVivo® version 9 was used alongside manual coding. The use of such technology has been encouraged by qualitative theorists (Patton, 2002; Silverman 2000) and is now well recognised as being advantageous in managing large data sets. NVivo® assists in the manipulation of the data allowing researchers to browse and code data efficiently. Ability to access coded data quickly and efficiently is a strength of such packages and in grounded theory where researchers needs to move back and forwards within coded data this can be helpful. Although data analysis software supports data management, actual interpretation of the data and decisions about initial, focused and theoretical coding remains dependent on researchers' engagement with data, critical thought processes and interpretation (Patton, 2002).

Researchers need to use such software in a judicious way acknowledging the potential to be over zealous in coding vast sets of data to the extent that coding becomes less interpretative and more reductionist in nature. In this study the software programme was found to be most helpful in initial/focused coding and retrieval of excerpts from coded transcripts but manual coding was preferred as more abstract concepts developed and concepts were merging and altering. These approaches supported the iterative nature of constant comparative data analysis which requires movement between transcripts; memoing; re-visiting initial and focused codes for refinement and re-interpretations in the light of further data.

Initial Coding

Initial coding is recommended by Charmaz (2006) which involves scrutiny of transcripts on a line-by-line basis. Although each line of data does not necessarily contain a full sentence or idea close examination of data can focus attention and prompt researchers to see nuances in data that more broad coding would not uncover (Charmaz, 2006). Such coding followed by section by section or incident by incident can produce various ideas which can then be developed. This theory development and adherence to the data through close coding at the micro-level is seen as evidence of the strength of the study.

An example of line-by-line coding from this study is provided to demonstrate the way that initial coding was used in this study (see Table 4). In this example the mother Norma was explaining that if her child has a minor infection it is

important that the specialists review her condition when she attends for regular treatment.

Table 4. Line-by-line coding example

Initial coding	Extract from transcript
<i>your child</i>	Norma: Yeah. You know, it's your child at the end of the day. You don't want them to... you make
<i>making sure</i>	sure she's okay. The cold, I made sure that somebody was going to see her, because I know
<i>knowing child</i>	she's prone to chest infections.
<i>knowing condition</i>	I: Right, aha. Norma: So I know that if she's got something like that, they need to treat that, not erm, give her drugs that she's normally going to get; she needs to be
<i>knowing treatment responsibility to make sure</i>	treated for that first and then she needs to get that later, but if you have... you have to make sure that this is happening.
	I: I see. So, is it always you that goes to hospital with her?
	Norma: Yeah, yeah.
	I: Would you feel happy with someone else going with her one week?
<i>not knowing</i>	Norma: No, 'cos they wouldn't know what was happening.
	I: Aha.Yeah.
<i>alone</i>	Norma: I mean, my mum's been with me before, but not actually been in on her own with her, she has called in if it's the school holidays or something and then taken my other daughter off into town, otherwise you're just tearing your hair out with her...em, but she hasn't actually done the ..I mean, she has said, you know, that she would do it.
<i>knowing the right treatment saying something that situation</i>	I: Yeah. What would put you off her doing that? Norma: I know what's supposed to happen , you know.. and I don't think that she would say anything. I mean, she is like me, but I don't think in that situation she would.

A number of these initial codes were later developed into concepts that became central to the emerging theory, for example, ***your child*** and ***making sure*** were

further explored in interviews and eventually were recognised as parents being ***on guard*** for their child. Similarly, ***knowing*** and ***not knowing*** had prompted theoretical sampling to find parents with on-going experiences to see if their perspectives differed.

At the initial coding stages, the urge to understand the data through an existing theoretical framework was tempting as I grappled with the dense information provided by parents. Earlier I confessed to a tendency to want to create order and at times the coding and exploration of different possible directions for the analysis was challenging. Such uncertainty and "messiness" has been recognised as a potential difficulty for researchers, however, in research there is purpose to the "mess" as it facilitates a change of direction from the taken for granted knowledge and understandings of practice and allows a different perspective to be adopted (Cook, 2009). Cook (2009) argues that it is in this state that re-framing can take place, so this messy area is important as the space between the known and the nearly known. The parallels with the processes undertaken to create a grounded theory from the raw data from my interviews were very apparent to me and enabled perseverance with initial coding and exploration of various interpretations of the data. The discovery of new knowledge or perspectives is the purpose of the grounded theory approach and it seems that this does involve the researcher in various explorations of concepts that may later be altered or even set aside as further data clarifies the emerging theory.

Memo Development

Having established initial codes for the data, typically grounded theory researchers move forward in development of theory through memo writing. This is a critical element in analysing the ideas that emerge from the coding (Charmaz, 2006) and enables initial and focussed coding to develop into abstract concepts for theory construction. Memos are written records of a researchers thinking during the study (Birks and Mills, 2011) providing an audit trail of the research and guiding theoretical sampling as new lines of enquiry emerge. The grounded theory researcher uses these memos to consider the codes, their properties and relationships between codes. Elliott and Lazenbatt (2005) view memoing as a way of sensitising researchers to their own personal biases allowing control of any distortion within the constant comparative analysis process. They argue that memoing is not only integral to the data analysis but also enhances the credibility of the findings.

In this study memoing was used throughout the research to develop my thinking and interpretation of the data. One of the concepts that emerged from the data coding was the notion of the unfamiliar territory that the hospital presented for many parents - this concept kept appearing in the coding although initially the codes included were:- alien world, outsider, not knowing and working it out for yourself. However, there were also examples of how other parents had become familiar with the world of the hospital or as a health care professional themselves had some "insider" perspective on the experiences (see Table 5). This area felt quite entangled to me and through writing memos I was eventually

able to see where the links between the codes may be and why apparently opposite view points were actually part of the same continuum. At one point I spent time considering and reading about cultural adaptation of immigrants to see if this shed any light on this area of being in 'alien territory' and later adjusting to this new place. In reality it was re-visiting the data and writing memos that helped me to develop the initial coding to a more advanced level and established the concepts - *landing in an alien world* and *from new parents to old hands*.

Table 5. Extracts from memos: concept of transition - new parents to old hands originally conceptualised as insider /outsider knowledge

Excerpts from memos that related to - insiders	
<p>First interview with Angela (nurse) - insider</p> <p>Example of her knowledge as an "insider" when looking at the transcript e.g. she talks about "not being too worried about him by then" so she put two chairs together and snoozed whilst waiting in an isolated room in the accident and emergency department for her son to be seen.</p> <p><i>Need to explore this more with other parents. It seems her professional knowledge and own assessment of her child's condition allowed her to feel relaxed enough to sleep. She also had the confidence to re-arrange the furniture in a way so that she could rest whilst he was asleep. The focus of this part of the interview was less about the long wait to see the doctor and how annoying and negative an experience that might be and more about how she coped with that, in a matter of fact way, because she knew "the score" almost.</i></p> <p>First interview with Graham - outsider (but married to Angela a nurse/insider)</p> <p>Example of his "outsider" status was acknowledged by himself really. He spoke of his lack of knowledge and appreciation of the gravity of the situation when some years earlier his daughter had been admitted in an emergency with a life threatening illness. It was only later when this had been explained to him by his wife and other professionals that he appreciated how dangerous it had been. He then realised the outcome could have been very different and their lives could have been changed forever.</p> <p><i>In this situation his "outsider" status and lack of knowledge almost protected him as he didn't know until later how serious the situation was - it seems that the actions of the staff made him feel safe -is this because of the way they dealt with it or his general attitude to health care professionals -trusting them to know what to do? Need to explore this notion more with Graham and others to understand this better.</i></p>	

You don't know what you don't know - so judgement of danger or risk may relate to ability of professionals to make parent feel confident the staff know what to do and/or is it related to the parents' beliefs or scepticism about professionals knowing best?

First interview with Norma - experienced "regular" parent - ?insider knowledge now

This mum had regular contact with the hospital and had developed a great deal of knowledge about her child's condition and the hospital. She talked about knowing "*what is supposed to happen*", she explained the differences between the "new ones" and herself as being "awful" for the new mums because - people can make you feel neurotic; you don't know what is happening.

As an experienced mum -"insider" - she knew what was to happen, what was actually happening and alerted staff if things were not getting done. She knew quite a lot of the staff and picked out the faces "you know, to ask for help". Decisions seem to be made by professionals with her and they trusted her judgements generally. ?some pros and cons to this -responsibility.

Questions here about moving from being an outsider and becoming an insider -not through professional qualifications but by observation and experience.

First interview with Gina -insider

Gina related the whole story in brief in this first interview and subsequent interviews she expanded and gave further depth to her initial account. The transcript contains examples of her as a "rookie" where she felt vulnerable, was compliant and expected the professionals to have the answers later she spoke as a "seasoned" parent who went prepared (taking food and drink as knew the wait would be a long one), knew the rules (best to leave ward when he was in theatre and come back rather than sit anxiously at bedside) and had "no expectations" when going to hospital as was "hit and miss" .

The apparent movement from being an outsider to an insider of the hospital world seems to be due to the parents finding things out for themselves and knowing better the next time. The help to make this journey seems to come from themselves adapting to the situation. The environment and the procedures are less alien and unfamiliar and they have learned from experience not to go with certain expectations which seems to have made it more manageable for them.

? look at cultural adaptation (becoming familiar within an alien environment)

? guarded alliance theory seems to also fit with and explain some of the perspectives described about parents' attitudes to professionals

From these early memos relating to insiders and outsiders this concept developed through further exploration in subsequent interviews and memos until the concept altered to be recognised as the transition from being new parents to old hands (see chapter 6).

In grounded theory there is opportunity at all points in data collection to explore new leads. This can be through re-visiting earlier respondents to test out ideas

which have emerged in later interviews or by seeking out new participants to try to illuminate new concepts which have emerged and need to be tested out. Constant comparative analysis (Charmaz, 2006) allows the researcher to compare data looking for aspects which are similar or different. At times in this process I did have to remind myself that the aim was to look for both ends of the spectrum as there was a tendency to favour similarities in the data as it confirmed my hunches and initial coding decisions. Recognition of this tendency meant further comparison and exploration needed to take place to ensure that any positive personal bias was minimised in the analysis. It was often at these moments of realisation that new insights were actually gained. An example of this was the way that many parents gave negative stories of events in hospital quickly followed by moderation of their account and tolerance of this when making an overall assessment of the experience. I found this notion of holding two quite opposing views of an experience difficult to understand but the similarities in accounts recurred regularly then I re-looked at all of the initial coding, looking for data which differed from these findings and then was more able to understand the phenomenon more fully.

Focused coding

The process of focused coding involves identification of the most significant or frequently occurring codes, bringing them together in one category (Charmaz, 2006). In constructivist grounded theory focused coding is the second phase of coding and is a more conceptual and selective level of coding compared to the detailed micro-level coding initially employed. The initial coding provides indications of significant areas for further analysis and exploration but it is the

focused coding that influences the direction of subsequent data collection and analysis (see Appendix 15). Moving analysis from initial coding to focused coding requires researchers to select initial codes that enable data to be further categorised in a more comprehensive and definitive manner. These steps condense data, distilling from it focused areas for subsequent exploration using the constant comparative analysis method central to this methodology. These focused codes cut across interview data enabling links and comparisons to be made between participant's experiences, personal responses and interpretations. Codes that were devised to fit with a specific incident arising in one set of interview data may shed light on a similar situation in a different interview. Equally, initial codes may appear quite dissimilar across interviews but with focused coding and further data gathering and analysis to refine the category the codes may actually show a connection (see Appendix 15). There is a continuing process of re-checking existing data as new information or understandings arise and the need to return to participants to re-visit issues or explore emerging concepts in more depth with them. In this study the serial nature of the interviews with the parents enabled this process to occur naturally in later interviews whilst also providing opportunity to share and discuss with parents the emerging concepts of the grounded theory. Following grounded theory approach, coding continues to be an iterative, non-linear process where new concepts can arise at any point in the data gathering or analysis prompting re-consideration of concepts within the emerging grounded theory.

An example of how focused coding was used in this study was the reduction of initial codes connected with parents entry into the hospital experience as they were subsumed under the focussed code of *landing*. (see Table 6).

Table 6. An example of initial and focused coding

Initial codes	Focused code
Shock of finding self in situation Sights and sounds of hospital Exposure to sick children Strange place Thrown into situation Sudden change Moment life changed Something was wrong No choice Unfamiliar Head spinning	Landing

Some initial codes seemed to have few links to enable drawing them together in a focused code, it was only after several journeys back and forwards between data and further contact with parents that connections started to make sense. Through an iterative process of transcript analysis, further data collection and re-visiting the coding, patterns began to emerge. In initial interviews parents often talked about their first experience of their child being hospitalised and these accounts detailed their life before that day and the strangeness of this new hospital experience. Initial coding reflected these narratives and then focused coding drew together the codes under the more explanatory focused code of *two worlds* (see Table 7). In other areas of the data initial coding appeared to have opposing meanings but through further analysis and

memoing it became apparent that there was a strong link between these codes. An example of this was that a number of initial codes alluded to parents firstly trying to find out information about the situation they found themselves in and later having greater understanding of this situation. The focused codes for these key areas were labelled as *searching for clues* and *making sense of the clues*.

Table 7. Examples of initial and focused codes

Initial codes	Focused codes
Normal life Familiar world Regular day Strange environment Alien place	Two worlds
Being in the dark Not knowing New to this	Searching for clues
Now know Old hands Being alone Interpreting	Making sense of the clues

Charmaz (2006) views the two phases of initial and focused coding as being essential. Initial coding enables the study of fragments of the data and then data is re-examined against more focused codes to develop categories for the

construction of the grounded theory. The next step in data coding taking Charmaz's (2006) approach is theoretical coding. This type of coding follows the focussed codes to identify potential relationships between the categories developed in the focused codes. The theoretical codes are developed through using constant comparative data analysis, memoing and diagramming to enable increasingly abstract concepts to emerge that connect the categories together in a cohesive explanatory theory. Charmaz (2006) takes a similar view at this point to Glaser (1992) as both see theoretical coding as a means of integrating the pieces of the story back together having studied the individual pieces of the story at a detailed level. The theoretical codes enable the analytic story to be told in a coherent way, conceptualising the links between the focused codes and moving the analysis to a higher theoretical level (Birks and Mills, 2011; Charmaz 2006).

Theoretical Sensitivity

The term theoretical sensitivity is used to describe the way that the grounded theory researcher needs to immerse themselves in the data and to scrutinise it closely to sensitise themselves to the key concepts (Glaser, 1978). Sensitisation can be helped by previous personal and professional experiences and knowledge of the relevant literature connected to the study (Birks and Mills, 2011). However, there is a fine line between this being helpful and the researcher relying on previous assumptions or existing research instead of searching for fresh meaning and explanation (Kelle, 2007; Birks and Mills, 2011). The nature of constant comparative analysis in grounded theory requires the researcher to maintain a constant dialogue with the data whilst using experience and literature to support their explorations thus sensitising

researchers to the concepts (Holloway and Todres, 2006). Concept development is recognised as a non-linear process (Charmaz, 2006; Glaser, 1978) with researchers needing to be open to moving backwards and forwards in the pursuit of exploring and fully developing the concepts. There is a need to consider literature; code data: build categories; develop memos and follow up leads in the data as they occur. Hoare et al (2012) captured this process well when they described these activities as "dancing with data" (p.240) to enhance theoretical sensitivity.

An example of theoretical sensitivity development in this study was the gradual recognition and sensitivity to the ways that parents were describing their need for information that they could understand. The importance of communicating with parents was perhaps such a 'taken for granted' concept for me that initially this was not the focus of my attention and initial interviews with some participants were so packed with information that it took time after the interview to reflect and absorb some of the detail and consider follow up questions to understand the data better. The importance of information for parents was not a new idea for me given my previous children's nursing experience and its coverage in past literature (Farrell and Frost, 1992; Darbyshire, 1994; Hutchfield 1999; Hallström et al, 2002). However, I became sensitised to the key concept of the parental need for 'information with meaning' from listening carefully to the parents and probing further in interviews to gain an understanding of exactly what it was about these inter-actions that mattered to parents. Initial coding, memoing and re-visiting the transcripts all played a part in developing theoretical sensitivity to the issue which then prompted me to seek out diversity in participants experiences to explore the concept from different perspectives. Charmaz (2006) advises that the researcher should explore the dimensions of

the category from varied vantage points to gain a full understanding of the category. In addition, returning time and again to the transcripts helped me to find fresh understanding of this very familiar idea that parents need information. The new elements emerging to the familiar concept of communication was the recognition of professional interpretation of information as being crucial, as well as the specific meaning of the information for their child and family in the present and the future.

From the data analysis a picture began to build up of parents in a range of different situations and settings who felt that they could not always make sense of the information they were receiving. Initial coding included:- 'being in the dark'; 'feeling around' and 'trying to work things out'. Parents lack of knowledge and understanding of information provided meant they were often left distressed and frustrated. Parents commented frequently that they had gained the knowledge they needed at a later date but if someone at the time could have explained the meaning of their comments to them this may have helped them. Attempts to use their existing life experience and knowledge appeared logical but often did not explain the clinical situation they were confronted with. Where information was forthcoming, timely and explained in a way that parents could understand, it was highly valued and praised, leading to very positive parent evaluations.

The concept of 'information with meaning' developed through my theoretical sensitivity to the communication issues parents were describing in the early interviews. I found that through theoretical sampling and constant comparative analysis I entered later interviews recognising and listening out for further

explanations and perspectives of this notion. This sensitisation helped in building a new and more comprehensive understanding of these familiar interactions between parents and professionals as if seen for the first time.

Theoretical Saturation

Theoretical saturation describes the point at which the data collection and analysis are revealing no new concepts important for development of the emerging theory (Charmaz, 2006) and this signals the end of data collection. Backman and Kyngäs (1999) suggest novice researchers need to understand that recognition of saturation can be problematic as it happens in unpredictable ways and may occur at different points within data collection depending on the individual study. Avoiding this problem requires researchers to be mindful that theoretical saturation is not about repetition in data but is the point at which new data no longer provides any new theoretical insights or new properties of the core theoretical categories (Charmaz, 2006). Dey (2007) illustrates this point further by viewing the saturated category as a sponge that has absorbed the maximum amount of water it can hold. The parallel drawn here is that there is no value in adding to a category already fully explained just as adding water to a saturated sponge bears no benefit. Theoretical saturation is dependent on data collection that encompasses a diverse range of data and theoretical sampling is a way of achieving such diversity (Glaser and Strauss, 1967). It is acknowledged that time and other resource restraints may affect the extent to which saturation can occur and this is known as premature closure (Glaser, 1978). Whilst it is debateable whether a state of theoretical saturation can ever

be fully achieved saturation can be recognised in abstract terms as being represented by a pattern or theme that makes sense to the researcher (Morse, 2007). In reality then, saturation requires the researcher's judgement to be used to determine that no further data is required (Wiener, 2007). It is at this point that Charmaz (2006) proposes that categories become theoretically abstract yet substantively grounded thus providing a connection between the data and the final theory.

Conclusion

In this chapter ethical considerations for this research were discussed. The methods used within grounded theory have been critiqued and their application within this study outlined: data collection through interviews; constant comparative analysis of data; memoing; theoretical sensitivity; theoretical sampling; theoretical saturation.

The next three chapters present the findings from the study which led to the development of the substantive grounded theory.

Chapter 5 Findings: Landing in an alien world

Introduction

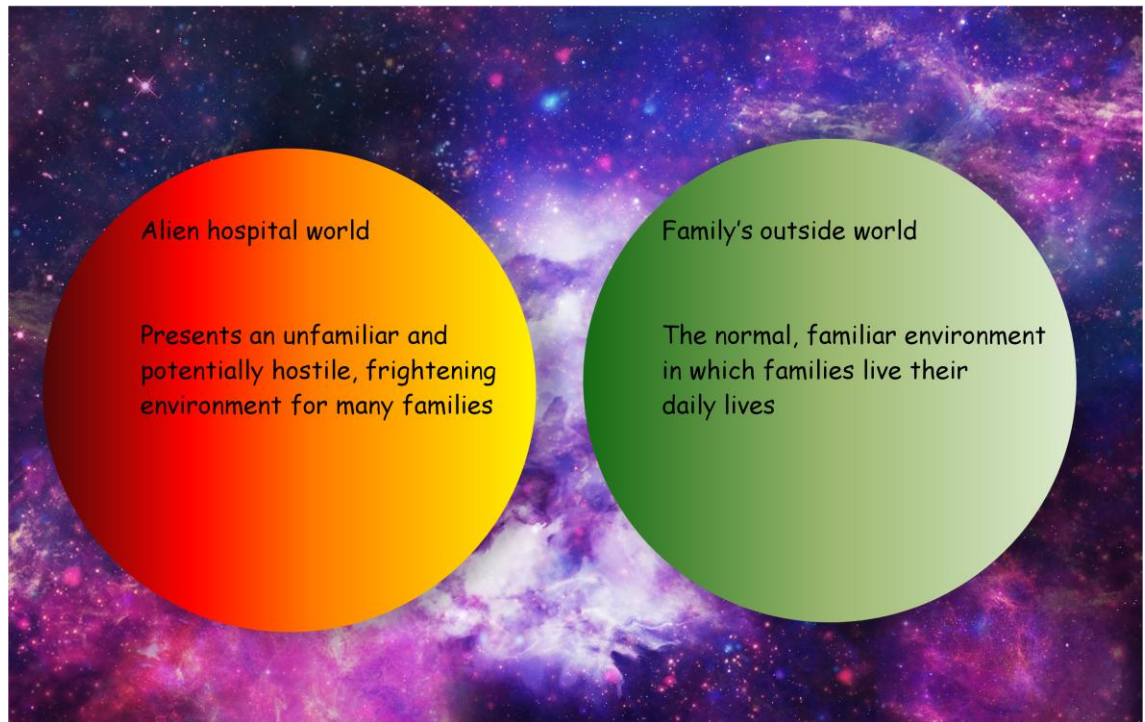
The following three chapters present the study's findings. This first chapter explores parents' initial landing in the unfamiliar hospital world and introduces the core category - parents 'protecting and advocating' for their child in an alien world. The core category emerged from analysis of parents' appraisal and response to their child's hospital experiences and is central and connected to the other categories. The second findings chapter, explores transition from being *new parents* to *old hands* and the third, presents parents' judgements and responses. In this chapter, findings are presented using the following sub-headings:

- *Two worlds - family's outside world and the alien world*
- *Landing suddenly and unexpectedly*
- *Biographical disruption*
- *Heightened emotions*
- *Anticipation of short or long term in this world*

Two Worlds

The *invivo* labelled category of the 'alien world' reflected the unfamiliar territory that parents felt that they had landed in when they found themselves in a situation where their child needed hospital care (see Figure 3).

Figure 3. Two worlds - alien hospital world and family's outside world



Parents perceived that they had left behind the outside world in which they usually lived and found themselves in a place where it was difficult for them to assess dangers and know the best pathways for their child. Parents recounted their initial experience of their child's hospitalisation as a shock and parents described heightened emotion and anxiety in this situation. Two worlds seemed to be in existence for the parents; 'the family's normal outside world' where they lived and which was familiar to them and then there was 'the alien and potentially hostile, frightening' world of the hospital (see Figure 3). Entry into this alien hospital world was not something that parents had a choice about, a set of circumstances often beyond their control resulted in them suddenly finding themselves in this situation.

The notion that most parents will harbour some degree of fear of their child being ill or injured during their lifetime may not be a surprising one to most people. In the family's normal outside world, most parents will constantly assess the risks of everyday life and respond, on behalf of their child, in their role as their prime protector and advocate. Sudden entry into the new and alien world of the hospital may have felt particularly shocking for parents as it presented unknown dangers which were difficult for them to accurately assess and act upon due to their unfamiliarity.

Whilst protecting and advocating for your child may be seen as fundamental and natural for most parents finding themselves in hospital presented many challenges to these roles. To be able to protect their child, parents need to be able to determine real and potential dangers and respond to them. Equally to advocate for their child parents need to determine what their child needs and then ensure they act on their child's behalf to secure what is needed. In the alien world of the hospital, parents were often hyper-vigilant as they remained 'on guard' whilst they determined how best to fulfil what they saw as their responsibilities. They recounted searching, scanning and appraising the territory for 'clues' to help them in their responses and to enable them to advocate 'on behalf' of their child.

Landing - suddenly and unexpectedly

Although there were a range of circumstances which precipitated the child and parents' arrival in this different world, there was usually an unexpected element for the parents in each account. The sudden change and lack of anticipation or

preparation accentuated the shock for parents adding to their dismay and difficulties coping with the situation. Parents' descriptions of 'suddenly' finding themselves in this different world did not necessarily relate to timescale or degree of urgency of the child's illness or injury but indicated the realisation and sharp contrast for them between these two worlds. For one family, the anticipation of a delivery of a normal healthy baby suddenly changed for both parents as they realised that "something was wrong". Understandably the two parents had very different experiences of the birth and their individual moment of realisation was also different.

Gina: ... we went into the operating theatre and we were talking and I felt absolutely great. Erm, and he was just like... they were saying "oh, mum's doing fine" you know..

A little later, following the baby's birth by caesarean section, the mum goes on to recall -

...then the registrar came and said: "we need to move this baby", so they all came in, the registrar was there and they whipped him away and we were like "what's going on?" ..., I was like all over the place...

The father's recollections of the birth also indicates his early, sharp and sudden realisation that something was wrong but at the same time not knowing what it was or the level of danger in the situation.

David: ... but they weren't overly worried, so when it came to the birth, we were expecting everything to be okay, with a little few caveats, but like.. but then he was born and then the... I just knew something was wrong and I don't think he.. I don't think the nurse or the doctor really sort of like

had that feeling, you know? And I just kept thinking like, there's something wrong here, there's something not right. I don't know what it is and like, 'cos obviously your brain's going like 100 mile an hour and you think there's something wrong, there's something just not right...

Recollections of their 'landing' in the hospital world was usually retold by parents in detail and in the chronological order in which they experienced it. Parents seemed to want to convey the normality of their 'world' leading up to the sudden shock of the unexpected event that jolted them from their outside world into the hospital world. The anticipated future for their child and family was altered in these moments and it was as if they wanted the listener to really appreciate how shocking this was for them. They provided a lot of detail about the events leading up to the important moment when they realised their situation had changed. This heralded them stepping from being parents in the 'outside world' to joining a different set of parents as they landed in the 'alien hospital world'.

Brian: I mean you're at work and the next thing you know, you think, "Christ, how did I get to be in the Central Hospital?"...

... Yeah, that's right. I was kind of doing work and then that, you think 'bloody hell'.

It was not only their personal situation that was alien to them: part of the shock for some parents was their exposure to the sights and sounds of other families within the children's hospital ward or assessment unit.

Brian: ...there was kids in there with all sorts. I mean, there was like a boy that had a heart defect; there was a child that was completely disabled and on breathing apparatus and stuff. So we were in amongst all of this going on...And you're sitting there thinking "bloody hell". You know. .. so it was a strange ward to be in. 'Cos you're thrown right into it, aren't you...

Although Angela was a children's nurse she also commented on the sights and sounds of the accident and emergency department when she was admitted with her young son who had abdominal pain and vomiting.

Angela: Em, that was awful, because it was a Sunday night after the local derby match and casualty was very busy and there was blood all over the floor and people screaming and it was awful. Em, but she [the nurse] said "we've got you a room" and she took us straight round the corner to the room and then said "somebody will be in to see you in a while" and then we sat there a couple of hours before anyone appeared ...You could hear it was busy and you could hear people screaming; you could hear babies crying.

Angela was in a different position to the parents who had no experience in a hospital before and her comments about the sights and sounds of the department she explained related mainly to her shock that children were being treated within this adult environment. She was also in a position to make her own judgement that her son was probably not requiring admission so was able to settle both herself and her son while they waited.

Biographical Disruption

Although the original focus of this study was about hospital care it became apparent that the entire experience for parents of their child having an injury, illness or condition could not be isolated from the hospital experience. The shock for parents of the landing was not only about being in hospital but was also about the child's illness, injury or condition. In reality, the child's hospitalisation involved much more than a change of physical environment and entry to a hospital building. The requirement for hospital care whether short lived or on-going, signalled a level of seriousness and therefore potential danger in terms of their child's health and well being. The parents' use of the word "world" to describe what they felt they had entered seems to capture clearly the notion of the entire place in which they found themselves in terms of physical, social and emotional existence. This unexpected event and its repercussions threatened the child and family's biography and the potential impact of this on their past, present and future lives was evident to them as they tried to cope in this new and strange world.

Gina: ... *Erm, so when we went for the six week check, erm, the doctor just said "I think there's something wrong with your baby; I don't really know what. Erm, I think he might have short limbs". Erm, and there was just like all of these things that he came out with and we'd sort of gone really just expecting him to say "oh, he's just having trouble feeding". You know, it... 'Cos he lost quite a lot of weight erm, and it was just like "Oh my God" you know, like a real shock.*

For some entry into the hospital world was a permanent and extensive change to their lives, for others there was a temporary change to their lives but also a

realisation that they had brushed with the danger of a permanent change for their child, family and their own lives. The shock of the events was relayed vividly in their recollections as if they were back at the scene. In the following extract Graham reflects on an emergency admission with his daughter Louise with meningitis from which she fully recovered but the realisation of how different the outcome might have been.

Graham: ...when Louise had meningitis, you know and, so that felt quite different, you know, it felt much more like an emergency in a way, although as I say I'm not even sure that I fully realised at the time how serious it was. I guess I didn't have all the medical insight into what was going on at the time, but I think at the time and certainly looking back now, I guess the thing that mattered so much was the fact that they acted so quickly in that case, it's this thing isn't it, of recognising when something is an emergency and dealing with it as such. So clearly that matters and that mattered to us and would have just...had that not been the case, you know, you can't start to imagine the difference it might have had on Louise's life and on our lives and so on,

In the families where there was chronic illness and on-going hospital experiences there was biographical disruption as their lives were altered, re-framed and the changes that illness or injury had brought for them was accommodated. The disruption of normality and the alteration to the family's anticipated future was articulated very clearly in many of the interviews.

Gina: ... Because, I mean he was born just before the summer holidays and we were thinking oh, that'll be great, because we'll have the summer

holidays and we can all be together and, you know, in your head, this lovely family idea and then obviously it wasn't ideal...

The on-going disruption of long term care on the child, siblings and parents was also evident in interviews with Norma as her daughter awaited a possible lengthy admission for treatment.

Norma: ...'cos I mean at one point, I was sort of saying "oh wait 'til I've finished my course at the end of June" and then you think no, 'cos I don't want it on the school holidays. And then they're bridesmaids, the pair of them, for their half sister in a month, just under a month's time. So she wanted to be there for that as well...so that sort of goes on hold...we haven't got bridesmaids dresses yet , 'cos we didn't know if she was going to be in hospital, out of hospital, so that looks like it's going ahead now. We'll have to get that sorted.

Interestingly not all of the parents related their initial experience of landing in this hospital world in quite the same terms. Wendy and Mary both recounted their experiences in very positive terms. Analysing and comparing individual cases where there is a divergence from the main categories emerging in a study is seen as critically important as it helps the researcher to build up a more complete picture of the categories (Charmaz, 2006).

Wendy took her daughter to the GPs to be assessed as she had lost weight rapidly and had been suffering with a frequent thrush infection. Throughout the interview she was very positive about her experiences with her child in hospital and since discharge to the specialist team.

Wendy: It was, yes. 'Cos, erm, I didn't actually go to the doctor's for that; it was... she kept getting thrush all the time and I went for that, but I had noticed she was losing weight as well, so I thought I'd mention that while she was there, 'cos she was still eating the right amount, but she had lost a stone in about five weeks. So, but like I say, she was still eating and everything, so I thought it might be something, so I thought I'd mention it and she said that because thrush can be one of the signs of diabetes, then we'll do a routine blood test. She went "nothing will come of it; it'll be fine..." but... but then obviously, she has got it.

She was very matter of fact and calm when relating this initial story and the subsequent phone call from the GP to tell her she needed to go to the hospital as her daughter did have diabetes. This contrasted with many other parents accounts of their 'landings'. Whilst clearly still unexpected and a shock for this mum her recounting of the story was different. On the way to the hospital she recalled being worried about what the ward would be like as she remembered her own poor experiences as an adult in hospital. However, once she arrived she was quickly, pleasantly surprised by the environment and the staff. Her whole care experience was described in very positive terms and there was only one event which she described as less positive (which will be discussed elsewhere). A key and repeated message from this mum was that all of the health professionals within the hospital and community had been there for the family from the beginning - they had answered all of their questions, provided emotional support, been available to them at any time and had demonstrated that they cared about their child and the whole family. Analysis of this individual case seems to support the notion that this mum did not feel alone in protecting

and advocating for her child in this strange world: instead, she had the professionals 'on her side' as well.

Mary, like Wendy, was impressed with staff during her hospital experience. A child-friendly approach and focus on the child's needs were highly valued.

Mary: ... it was a male nurse. And I thought he was absolutely brilliant with her. I thought it was great. He was telling her everything he was doing as he was doing it, why he was doing it. He really explained. And it was all about what he needed for her. And I thought he was really good.

Heightened Emotions

At the time of their first or early experiences the sudden shock or realisation for parents that they had arrived in a very unfamiliar world was evident, as described earlier. Parents described the emotional impact of the experience as feeling highly emotional, anxious and vulnerable. Some anxieties and vulnerability stemmed from their uncertainty about the outcome for their child but their lack of understanding of situations also exaggerated their concerns. Parents expressed some surprise at their own emotional responses to the experiences and their impact on them personally.

In the extract below, Brian explained that he had been in the army and been involved in active combat before, so he felt he had seen all types of traumatic and distressing situations, yet he felt such heightened emotions at the time of his baby's hospital admission he wondered how other parents coped who had not had his experiences.

Brian: ...No. And as I said; I've seen things, you know, I've seen... It's not as though I've had a closeted life, either. It wasn't as though, you

know, it was a real shock to me, because I've seen other things and then... yeah, so maybe that just shows you the impact, I think. Erm, if I'd been a normal person growing up in a normal world and... You know, normal job and stuff, then that happens, it would have been traumatic enough, you know. But... I think just with the kind of life experience I've had before it, I've kind of seen things before and even then, it was still a big thing, you know.

When parents spoke of their worries and heightened emotions in relation to their child's condition, the child's size, suffering, vulnerability and dependence was highlighted. The dependency of both child and parent on professionals to help them change the situation for the better was also evident from their recollections. In this example, a father, explains how different it feels when it is a child that is ill rather than an adult.

Brian: ...Cos again, you're in other people's hands as well, you know. And I don't know... there's something about children that you don't know. You know, like... a vulnerability, maybe.. You know, when they're that small as well and something happens to them and you think: 'gosh'. It's okay if you're an adult, or... you know, you can cope with that really, but not children.

Parents described being emotionally vulnerable and receiving unwelcome news from professionals in a way that was insensitive to their emotional state and

where the meaning and implications of information was not provided. In these situations parents were left feeling bereft and described withdrawing, being silent or sitting back in their normal outside world with these upsetting thoughts and words in their minds. In this example, Gina, described being told at the six week post-natal hospital appointment that their child had some problems and although doctors did not have a diagnosis for this the doctor did comment that the baby had short limbs.

Gina: Yeah. I think it must be difficult though, because everybody, everybody's different, aren't they? And you know, I could say something to you that could really offend you or upset you and then I could say it to somebody else, who... but I think obviously because of their profession, they've got to think a little bit more than we would. You know? And especially like at first, obviously you're very raw and you're very emotional ...

Parents did not seem to expect professionals to provide emotional support to themselves although their stories revealed their need for such support. They viewed the role of health professionals as primarily being about the child's care and not about their needs as a parent. The times when professionals did focus on parents and acknowledged how difficult situations must be for them, were commented upon and valued by parents. Parents were stoical in their determination to "keep going" for the sake of their child and frequently commented that they had no choice. It was their child. The unspoken dialogue here was that for the love of their child they would tolerate the hardships.

In this extract, Gina, spontaneously comments on the one doctor who actually asked about her well being. At this point she had been through a number of admissions and experiences with her child.

Gina: Erm, I think the most human was probably the specialist, Dr. V. She was... she actually said "and how are you doing?" And she's the only one who's ever asked that...Yeah. And I think that's understandable, because their job really is to look after the child, isn't it? And specialism, but it is all about caring, but I can honestly say: she's the only one who actually said: "and how are you doing?" You know, erm, and I think sometimes you just wanted that... You know, just somebody to say.. because I think sometimes we're quite stoical people. You know; we just get on with things and... and I do wonder about people who are not very strong. How they would cope and how, you know, and all the paperwork and the appointments and getting there. And I know that's the same for everybody...

Apart from the heightened emotions felt by the parents at the time of the experiences with their child there was an acknowledgement by parents of the emotional toll their experiences had taken on them. Where parents had short term experiences in this hospital world they were very relieved and felt lucky to be able to return to their normal familiar outside world. However, they also described feeling guilt and empathy for those children and families who were still in the hospital or were going to be starting a long term relationship with the services. In the following extracts Brian reflects on his short-lived experience in

hospital with his child and how different the hospital world was from the outside one.

(First interview) Brian: And at the end of the day we were lucky...it is another world and, you know, even when you get home on a Friday night, I remember thinking: 'gosh, they're still in there', you know?

In the second interview although he was making the same key points about his hospital experience with his son there was a sense of him trying to further explain it to me in different and more visual terms. His emphasis on just how strange it all was appears much stronger in his use of words to describe it and the impact is evident as he comments about reflecting on their family life after this experience and realising they were lucky to have escaped from this world.

(Second Interview) Brian: ...you are just right in there..it is so strange, it is like an alien world. You just don't understand it all, it's all so strange. It makes you take stock of everything else and remember how lucky you are.

For those parents who had longer term experiences of hospital care, their entry and adjustment to this world was recognised as having taken an emotional toll on them.

David: you're thinking you're coping, because I always cope and I'm... the sort of person I am, I'm thinking: nothing ever challenges me, you know, I get on and get on and suddenly, you need to reflect... it wasn't until..six months later when I looked back... (David then related decisions

he had made and mistakes he felt he made that he thought were related to the emotional pressure at the time.)

There was also a sense that there was no choice for parents in facing these difficult experiences and the unspoken message was that it was for their child's sake that they had to continue to deal with these on-going, challenging and emotional situations.

Norma: ...people say "oh, you just get on with that.." yeah, you have to. "Oh, I don't know how you can do this; you know, do hospital every week; do hospital visits; go to work; look after a child and a dog and whatever else and go to college". You just do it.. You just get on with it. You have to.

Anticipation of short or long term in this world

Where parents perceived that the hospital experience was a one off experience, their efforts were focussed on 'getting through it' and 'out of it' as quickly as possible. They viewed stepping into this alien hospital world as temporary and saw themselves only as visitors, hoping and anticipating that this would not become their world.

Brian: We were on a ward for about four people and actually, this fractured skull compared to the kids that were in that room was nothing, 'cos there was kids in there with all sorts. I mean, there was like a boy that had a heart defect; there was a child that was completely disabled and on breathing apparatus and stuff. So we were in amongst all of this going on and we started feeling a little bit guilty, 'cos we only had a

fractured skull, to be honest, you know?...And you're sitting there thinking "bloody hell". You know. We're getting out of this eventually, we hope. But the people around the room aren't going to get out of theirs. It was a strange ward to be on, I don't know...if that was the norm or not.

Although Brian's family did only have to stay for a short time before they were discharged and were able to escape back to their own familiar outside world, the experience had a clear impact on them. The impact of witnessing the distress of the other families and catching a glimpse of their lives evoked feelings of guilt and sympathy. The father's memories of the sights he saw on the ward were a shock to him as he had suddenly found himself and his family close to other families for whom this was their regular world. At that point he still had some worries his baby's injury may have caused some long term damage so being surrounded by children with physical and learning difficulties was a frightening and physical reminder to him of the realities of these outcomes or dangers. When the father recounted his memories of that short hospital experience it is evident that it was a very traumatic and worrying experience for him. The fear and dread of what this could all mean for his son was all too clear in the interview.

Brian: Up to the CT, your head's spinning, really... Or maybe it's until you know he's going to be alright, kind of thing. But even then, we didn't, you know, until... I think it was the next day. So you're not sure even through the night, how he was... 'Cos that was my big fear, was if... well, I don't know what's in your head, but... damaging his brain, or, you know, stuff running out, it was that big a lump over his ears... stuff off his brain, or you know; you just don't know. And then, when they're that small, you

know, they don't talk anyway, so how do you know what's right or wrong, you know?

The father recollected that it was not until later in out-patients a full explanation of what they had witnessed and experienced was given, along with reassurances for the future. This type of information that was discovered by parents afterwards was given the *invivo* code of 'we now know' as this was frequently referred to by parents to explain their changed perspective on earlier experiences.

Parents who became frequent attenders at the hospital described similar experiences in learning information and fully understanding events at a later date. This experience of learning relevant information after events had occurred seemed to characterise parents' progression along the continuum from being new parent to old hands and their' personal lens altered as their personal life perspective changed.

Reflecting back on their initial entry into the world of the hospital, most parents described the experience as frightening and the "not knowing" was a central focus for their anxieties. Parents who became regular attenders or who had on-going contact described how they had adapted and become more familiar within hospital which helped them to cope better with their experiences. They felt they coped better now they were regulars than they did at the beginning and related this to how they now had more idea of what to expect and they controlled aspects of the experiences that they could control. In the following extract Gina relates how she has adapted to lengthy and unpredictable waiting times in hospitals as she has become a regular attender.

Gina: Well, we just don't even say a time now. We look at the time that you get the appointment, obviously and you make sure you are there, but, well we always make a joke of it, saying " just put your watches away when you go into the hospital", 'cos you know, just be prepared to be there all day, really...I used to allow an hour extra. Now I just write the whole day off, really.

Norma expressed a similar attitude when talking about the length of time it takes for her daughter's weekly treatment,

Norma: You know I think , almost I think life stops at the hospital, you're there, so you need to wait. Your life is there, but in reality, you've got other things going on; you've got children to pick up and not everyone has somebody else who could pick her up.

Similarly, Norma reflected on how different it was being a parent new to the hospital to being a regular parent with lots of hospital experience.

Norma: Very scary. 'Cos you didn't know anything.

Norma: Where I think if you were a new parent going through it , it would be awful. Where you know, if you're an old hand, you just sort of get on with it as such..and you've got an understanding of what's going on, where if you're just new into the situation , I think it would be far worse.

For some families there was also the acceptance and adaptation to their child's on-going health problems mirroring their adjustments to the hospital world. Many of these parents recognised that they had moved on from their initial 'landing' as a new parent and had become 'regulars', 'veterans' or 'old hands'.

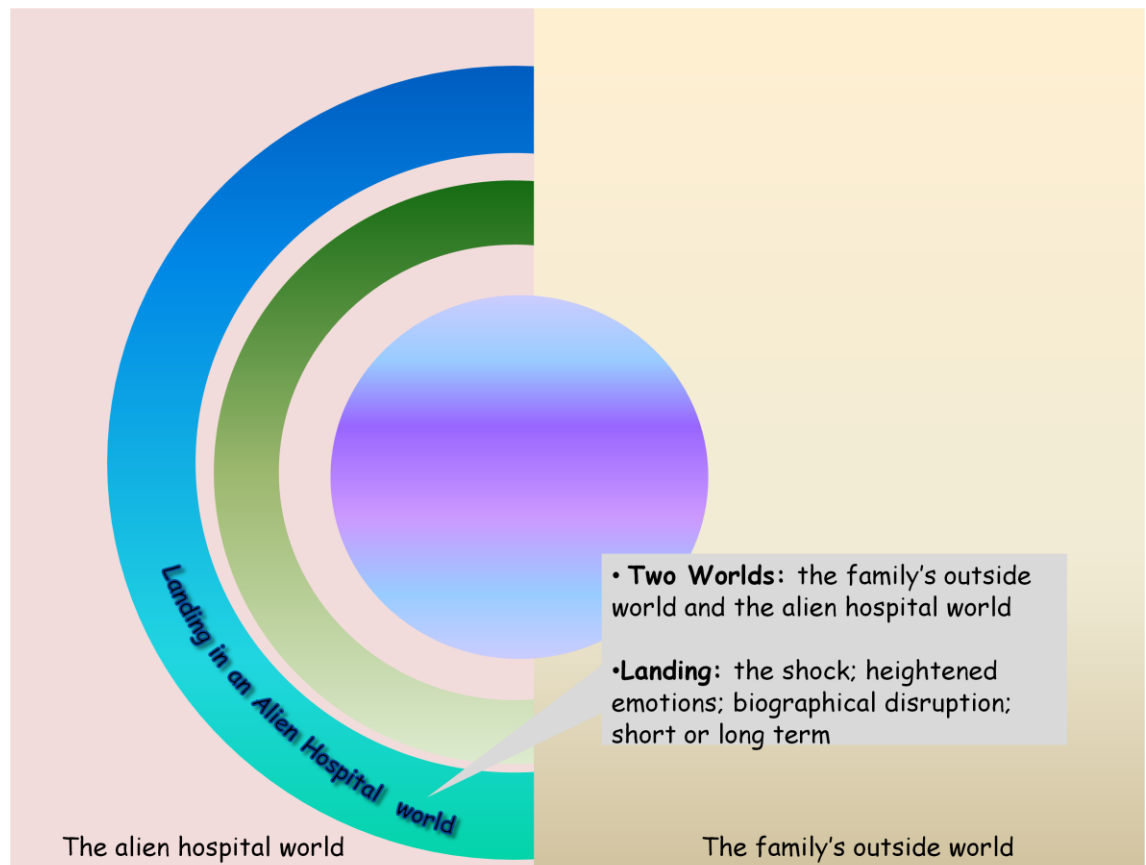
Recollections of their earlier experiences as new parents were seen by some as 'awful' and 'the worst time' - characterised by worries and fear but mainly 'not knowing'. The emotional toll of these earlier experiences was commented on by parents despite having moved on to a point at which they were now labelled in their own words as 'old hands'. On-going emotional pressures for families who became regulars at the hospital was expressed in their narratives. Unlike parents who had short term experiences and then escaped back to their normal lives the parents who became regulars at the hospital had to adapt, adjust and cope within this new world and the on-going pressures it brought to them for the sake of their child.

Conclusion

The impact of the sudden and unexpected nature of events that brought parents from their familiar "outside world" to the strange and unfamiliar world of hospital care has been illustrated here from the parents' accounts (see Figure 4). Parents struggled with not being able to continue to protect and advocate for their child in this situation due to the limits of their knowledge or understanding of the real dangers for their child. The repercussions of these events threatened the child and family's biography and the potential impact of this on their past, present and future lives is evident from the excerpts of the narratives (see Figure 4). For some parents this was a short lived experience and they were able to return to their familiar world but for others this was the start of a long term experience whereby they moved from being new to the situation to becoming 'regulars' or 'old hands'. In this next chapter this transition is

considered and examples from interviews will be used to highlight the critical elements.

Figure 4. Landing in an alien world



Chapter 6 Findings: From "new parents" to "old hands"

Introduction

In this chapter important aspects of the transition from being a 'new parent' to becoming an 'old hand' is documented from parents' perspectives. Their initial sense of being 'in the dark' led to a search for clues to help them understand the situation thus supporting their parental role as protector and advocate for their child. New parents arrived in this world with their own personal life perspective built up from their previous life and health care experiences, personal beliefs and values. This personal life perspective formed the lens through which they viewed and interpreted this 'alien world'. Their lens altered as they moved from feeling they were 'in the dark' to a place where they had better understanding of this world 'we now know'. Some parents felt alone as they moved through this journey of understanding whilst others described having allies who helped to interpret and translate the experiences within this world.

Findings are presented using the following sub-headings:

- *In the dark and not knowing*
- *Transition from new parents to old hands*
- *Giving information without meaning*
- *"we now know"*
- *Insider knowledge*
- *New parents - personal life perspective and lens*
- *Making sense of the clues and altering the lens*
- *Being alone or having allies*

In the dark and not knowing

Having landed in this alien territory, parents searched for clues to help them to make sense of this new world and its dangers. This was a world in which they now had to operate for their child's sake and they felt they needed to understand it. The feeling of being 'in the dark' and 'not knowing' what was happening or to happen was frightening for parents. It was their child's life, health and well-being at stake and the drive to protect and advocate was very strong. The unknown nature of the dangers presented by not only their child's illness or injury but also the staff and the treatments were all sources of worry, fear, anxiety and stress for parents. In addition, their own lack of ability to protect and advocate for their child caused distress and feelings of helplessness and vulnerability. Their descriptions of their feelings at that time often reflect heightened emotional states due to the situation they were in and their sense of 'not knowing' in this unfamiliar place. Whilst the time of entry into this world was usually recalled as frightening and stressful by parents, the extent to which this was felt or expressed depended on the context of the danger sensed by parents regardless of whether this was real or unreal. Their lack of knowledge of what the dangers and risks really were or how to interpret them added to their anxieties.

Transition from new parents to old hands

Parents recalled being more compliant and anxious as new parents as they were unsure of what was expected of them or what may happen during a hospital admission, investigation or out-patient appointment. Parents recognised their behaviours and perspectives had changed as they gained more first-hand experiences of these situations and they moved from being new parents to old hands within the hospital.

[In this extract Gina had been discussing the time that she realised that her son was not the only patient with a 9am out-patient appointment for a clinic, she then continued to talk about admissions to hospital]

Gina: ...especially when the days we've actually been admitted to hospital, you know, had like operations, that's what they do. Everybody gets the same time so..so I know that one now. So, now, I must admit, on the operations ones, say, if I'm ten minutes late or something, I don't feel bad, whereas before, I would have, you know, I'd always have been there, say, half an hour before, but I never get there, like, I'm always dead on time, or a little bit after...'cos I don't like being late, really, but..it's just the way it is.

Some parents commented on the impact of greater familiarity with the staff as they became more experienced as parents in this situation.

Norma: ...so she knows faces and they know you. You know, it makes your hospital stay a lot easier. If you know people; if you know the staff...They know the child. They know this isn't how she should be. You

know, they've seen her at good times. So it's not you being a neurotic mother, thinking oh, my child's really poorly or whatever; they can see it. erm, which is why I liked it at District hospital because we went weekly...they know her, so if I'd ring up and say "I've got a concern" .. bring her in, they'd have a look at her and say "yeah, you're right".

Some parents explained how they became more able to predict what was likely to happen in certain situations, for example, at out-patient appointments, investigations or admissions as they had been through these experiences before.

Gina: 'cos we used to go together [her and her husband], but there's so many appointments that you just can't afford the time...

I. No, I see.

Gina: and because, again, when it's something that you've already done, or are just outpatients, where you think: well we're not really going to get any information here, or they're not going to tell us very much, you feel like you can cope on your own, whereas in the beginning, we used to go together all the time because we didn't know what they were going to say and I think sometimes if you're on your own, you miss things and obviously it's easier.

There was also a sense that new parents were less likely than old hands to question professionals' advice, as new parents had limited knowledge and experience making them more dependent on professionals for direction.

Gina: So I think if we have to go back, it'll be okay [talking about a kidney scan that had to be abandoned as Thomas would not co-operate]. Erm, I don't know. 'Cos again, you start thinking, well, how necessary is it for us to do that? Is it..again, now I start asking myself, is that a critical thing to be having done, or should I say no, I'm not going to do that?

I: yes

Gina: ...whereas, like, in the beginning, if somebody said to me, take your child to hospital and do this, I'd have said "yeah, okay then". Whereas now I'm thinking "well, do we really need to do that?" what benefit is it going to have.

Gina provided another example of how her attitude to hospital admissions differed now from the earlier days.

Gina: ...I think we had to be there for 8 o'clock in the morning, or something. So normally I would have sort of like, got him up and stuffed the breakfast - actually I don't think he could eat - but I would have been you know, like "oh, we'll have to be ready; he's got to have his clothes on..."

I: Yeah. We've got to do all this

Gina: Whereas now, I'm much more like, "Well why does he need his clothes on?" you know, we're going in a car; we're going from the car park to the ward..and then he's going to get his clothes off, so..and I just left him in his jammies and maybe I was more relaxed...

Parents coped with their on-going experiences by adapting to this new world and by 'learning the ropes'. As parents observed in this environment they gathered information and armed with this information they were more prepared for subsequent experiences. They learned more about what the real dangers were for their child and what they need not worry themselves about as they became more knowledgeable about their child's condition.

Parents spoke about how they learned to adapt and control what they could control whilst learning to live in two worlds and navigate between them. Parents learned how to advocate for their child as they became more familiar with the way hospital systems worked and developed their own strategies to get the best for their child. Although parents adapted, gained knowledge in different ways and used different strategies their motivation and intent was the same, they all were acting to protect ('on guard') and advocate ('on behalf') for their child.

Looking back at their initial entry into the hospital world for most parents was described as frightening and "not knowing" was a central focus for their anxieties. *Regulars* or *old hands* described how they had adjusted and become more familiar within hospital helping them to cope better with experiences. Some of the examples they gave of how they coped better now they were old hands related to how they had more idea of what to expect and they controlled aspects of experiences that they could control.

Gina: I think it's a lot to do with our expectations now. I think because we know what to expect when we go in, we're much more prepared. I think in the beginning, you just... again, I think you just... because we're compliant people; because you do what the experts tell you, you just

expect to go and you do it and that'll happen and that'll be over and done with and there you go. Whereas now, I just think: you don't have any expectations now. Not in terms of, like, the level of care that you get, 'cos that has been absolutely first class, I cannot fault the level of care, but in terms of the waiting and sort of the people coming to speak to you and the sort of like 'what happens next' and stuff like that. I think, if you get somebody good, it's a real bonus.

Having been to hospital several times for operations parents had learned by experience that once the child had gone to theatre they faced a long wait for their return. In the early days they just sat and waited as they were frightened to leave the ward. However, with confidence and knowledge gained from previous experience they subsequently were prepared for this and left the ward once the child was in theatre.

Gina: But what was good with that was... the first couple of times he had an operation, we've just sat there. I don't think you had to, but I think we did, 'cos we just weren't sure. Whereas like, now, we've sort of... when he's gone into theatre, we've gone out, got something to eat and then come back.

I: Aha. Had you decided to do that, or did the staff say "do you want to go and we can..." ...do they ring you?

Gina: No. We just said "is it okay?"

As parents 'learned the ropes' they were more likely to be assertive or make an enquiry of staff where in their initial visits they waited to be directed by staff. It seems that new parents wait for staff to provide information and direction for

them but if this is not forthcoming they observe, seek out information and work out for themselves what is best for them to do.

Giving information without meaning

When given information but not having this explained in a meaningful way to them, parents described leaving the encounter even more worried, especially at times when they felt vulnerable. Their own lack of knowledge to enable them to fully interpret new information meant they could be left with fears and worries about potential dangers that may not be real. Professionals may not have appreciated the impact of their communications which for some families were etched in their memories.

Gina: And especially like at first, obviously you're very raw and you're very emotional and I think when we first saw Dr. F at that six weeks check, it didn't really compute to be honest; it just... and I remember we came home and we'd left Lucinda up at a friend's and she'd made tea and everything for us and we just had to go in there and eat our tea and just carry on as if... and inside, you're thinking: God, my child might have short limbs. What does that mean? Oh my God.

David: Oh, that was horrendous.

Gina: And obviously he was just doing his job, but...

David: You just felt there was an obsession to find it.

I: Right.

David: ...They'd made the decision that he had short limbs and now we have to prove it; prove that they were thinking: he is what he is; I've done all the measures... But why sow the seed in our head so many times? It was so many times.

I: Right.

David: And you just thought like "do you know how much we thought we were going to have a...(speech fades away) and that was awful.

Also in the absence of information 'with meaning' the parents later wondered if they were not being told everything.

Gina: But I remember at one point... he's got a file like that, as you can imagine, and I remember, after... I can't remember how many... how long it was, but I got to the point where I was thinking you must know and you're just not telling us.

The consultant confirmed that this was not the case and offered her the file to read to satisfy herself that everything that was in the notes had been discussed with them. Gina did explain that before Thomas was born she had little experience of health care and had a "naive" belief that health professionals knew everything and knew what to do. They were, in her eyes, the experts. Her experiences following Thomas's birth with these expert professionals gradually altered as she appreciated her own expertise. Her comments then could be a reflection of her existing belief that the experts did know everything and therefore they must just not be sharing this with them as parents.

Parents did not always understand information given by staff and were left with many unanswered questions. An example of this is given in the extract from an

interview with Graham where he described an incident when his daughter Louise had an appendicitis.

Graham: This sort of grumbled on for several days actually and in the end, they did end up operating, but I remember at that point, you know, a number of discussions and scans and x-rays or whatever else you know, going on and just generally feeling a bit kind of unclear on what was going on and almost wanting the whole thing simplified in black and white terms you know? ..Is it good or bad? Is it dangerous or okay? You know, and so on.

When parents were hearing new information about their child from health professionals they described occasions where they were immediately 'thinking ahead' a step further or even beyond that into their child's future. Continuity of the parent's role in guarding and advocating for their child meant that when given a piece of information they would then work out the consequences of that for the child and themselves. They saw themselves as the ones that would ultimately have to cope with the situation or deal with the outcomes. Parents were preparing themselves for the next dangers and how best to deal with them. At times this was about what this information would mean practically, for example, their child being on bed rest and being bored and the parent having to cope with their child's annoyance at this plan. Other occasions this was about the long term outcomes for their child and impact on their child's future life - parents were concerned with the child's past, present and future biography.

When parents were given information without any meaning attached to it the consequences for the child and the family were uppermost in the parents'

minds. Professionals delivering the information did not always seem to appreciate this when communicating with the parents. Parents were immediately thinking - what does this mean will happen? and how am I going to manage this? They knew that it would be their job to manage their child's reaction to interventions as well as their own responses and they needed to prepare or cajole their child to co-operate with the staff. This was all going through their mind from the moment that the clinician mentioned a test or a treatment strategy.

In this extract this mother explains what she was thinking as she was being given information in the fracture clinic,

*Angela: ...Half-way house he called it and then he says "you're seen by us and then you come back to the fracture clinic in the morning", so this seems to be what happened to everybody. That they say if it's anything to do with that, then it all happens through the fracture clinic. Erm, so I think they said take regular painkillers. Rest him. **'Cos they said he might have to rest for a week, at which point I nearly died. But erm, I just thought he's going to be so bored and I'll have to be off work as well...** But they said it might not be that, but he obviously is sore and we need to rest it.*

In this example practical consequences and problems associated with this message from the doctor are clearly immediately being processed in terms of the child, parents and family life.

These findings provide important insights into parents' perspectives when clinicians communicate information to them. Armed with this knowledge they can adapt their messages to parents taking into account this need for the

meaning of the information for the child, parents and family to be given. They can also be mindful that parents are perhaps thinking ahead a few steps and may need opportunity to discuss further ahead than the immediate situation.

"we now know"

There were several examples of parents not fully understanding, at the time, exactly what was being said or what was happening during their initial hospital experiences. Later, they were able to make more sense of the events or received further information which helped them to comprehend experiences. Some examples of this were when the information would have been useful to them 'at the time' as it could have allayed their fears or helped them to appreciate the dangers rather than having to interpret and risk misinterpreting the clues themselves. Other examples were where their subsequent knowledge gain meant they now appreciated in a very positive way the efforts of health professionals at the time. In this excerpt Gina explains that the doctors kept asking her the same questions whenever she took Thomas to hospital but they did not tell her why they were asking these questions.

Gina: ... and I was saying "what? Is there a significance" and he said "No no no no" and I was thinking: well, there must be, because you wouldn't keep asking those questions. If they'd sort of said to me "on occasion, children with special needs or children with this, you know, you have a problem with their teeth, or..." then I would have just said "okay. That's why you're asking", but it was like "let's have a look at his hands", 'cos he's only got like one line across his hands. That's an indication

apparently of children who have problems and you know, I thought: I'm not sure what context you're asking me these questions in. If you'd said to me: "It would be good if I could ask you about this, this and this, because then it might help us with that..." but it was just... again, there's no context around it; you just get asked things.

Similarly, in the same family they later learned information that they did not know at the time that they were dealing with the problems.

David: Well I... he had his operation on his eyes and he started walking at the same time and all of a sudden, there was a different child. He went from being like 'flat' and very slow and then all of a sudden, he just rocketed, because, obviously when you're walking, strengthen your legs and everything else, erm, your stomach is designed to be upright, you know, 'cos we learned that during the conversation with the NHS people.

Gina: He couldn't sit upright 'til he was two and a half.

David: And he couldn't see...but then he could see and I think it just opened like a massive world to him.

Parents explained a range of situations where they gained knowledge much later on, that would have been useful to have known at the time as it could have altered how they viewed or managed problems. In addition, some of this knowledge, may have alleviated some of their worries or misinterpretation of the clues and the dangers.

In this excerpt a father described how some weeks after discharge from hospital they were given explanatory information by the doctor at the follow up appointment.

*Brian: We had to go back in January or February, for like a... it was more an X-Ray, I think. I can't remember, or was it a scan. I don't know if they scanned him again, or whatever. And that was just in... She just said his head was forming fine again. Erm, 'cos I think at that age, she said the bones aren't... are pretty soft... but you don't know that though, you know? Like, because... **I know nothing about stuff like that**, but the fact that it was out over his ear was... It wasn't just even a little lump; his ear was there and his head was out there (demonstrates how big the swelling had been) and you think: "Gosh, is his brain swelling about there or...?" And then you go to that ward and you see disabled kids and you think... you know, is he going to be a one, you know? So...*

This extract demonstrates the situation where this father, at the time of the accident, had been trying to assess the danger for his baby with the knowledge he had at the time. He could see that the baby's head was very swollen and could feel this in his hands but did not know if this was his brain swelling up. He knew that this was a serious injury for a baby but did not fully understand the swelling and he said this was not explained to them at the time. When they were given the information initially it was given to them without an explanation of what the injury meant for the baby then or in the future. Knowing the possible consequences and the course of actions that needed to be taken by the clinical team could have alleviated the parents fears and helped them to feel that the team were doing the best for their baby.

The very brief information they were given, at the time, without explanation or an effort to make this meaningful for the parents had a profound effect on them. Later, at the follow-up appointment the parents were told more about head injuries in babies and then they felt more reassured. This further knowledge gleaned was about the anatomy and physiology of a baby's skull and the doctor explained about the gross swelling that the father had felt and seen on his baby's head. However, he did not have this explanation at the time of the admission to the hospital, he found this out later.

In this example the impact on parents of the language used by the doctor is very noticeable and was repeated several times in the interview with great emphasis by this father. The words used in such exchanges can trigger powerful imagery and in this case the use of the word "broken" inferred that the baby's head was unable to be repaired. The language used in this situation triggered frightening images for the parents but professionals can through careful choice of words create feelings of safety and reassurance for parents. There were examples in interviews where the language professionals used had made the parents feel they or their child mattered and that they were the parents' allies. These positive encounters with staff were highly valued by parents re-enforcing to them that they were not alone in this experience and that the people caring for their child valued them as individuals.

Insider Knowledge

Parents gained knowledge and understanding as they moved from being new parent to old hands and reached a point where they had a range of insider knowledge about the hospital world and how it worked that they used to help them as parents. This knowledge was used in their roles as protector and

advocate for their child but also to help them to cope by controlling aspects of the experiences that they could control and reducing some of the stressors they had encountered initially. In the extract below Norma explained how she was no longer able to bring her child straight to the specialist unit if she had a problem, she was first to be seen in the local hospital.

Norma: My sort of gripe with the whole system is that I have to go to the local hospital and I can't go straight to the specialist centre. . and they know that and I was like ..but they don't know my child. You know, we don't go there very often, so they don't know her..so they couldn't say "yes, we think there's something wrong". I'd rather come to you. "No, you're not allowed to. You have to go to your local hospital first". "But I don't want to; they don't know me".

The next time Norma needed to contact the local hospital about her daughter she used her knowledge of the processes and systems to enable her daughter to be seen locally by a Consultant from the specialist centre.

Norma: she's suddenly got a lump on her wrist that we don't know what it is, so I'd rang on Tuesday morning and said...I've got Lana and she's got 24hour open access- where to me, I would just turn up if I had open access, but I know from previous experience when I've done that "Oh no, you're not supposed to..you're supposed to ring us first". Right. Then they can get the notes from Hospital B transferred by the time we've got there. I think is how they sort of do it. erm, so I explained what had gone on. You know, she's got this lump and what do I do? Do I bring her in to you? Do I need an appointment? You know, what do I do? Erm, she said "Oh I'll speak to one of the doctors and I'll get them to ring you

back". I said "alright that's fine". But in the meantime, I'd rang Hospital B where Lana gets her methotrexate, [Lana had been on and off this drug and Hospital B had just been phoned by the specialist centre that week to order the drug again but Norma now knew that the drug was again to be cancelled].

So I thought right, I'll ring Hospital B and say "we don't need it now; don't bother ordering it" [the hospital said they already knew this as the specialist centre had emailed them] I said also "put her notes somewhere, because they're going to come and get them from the local hospital, I think". So I was telling her what was going on and actually, one of the consultants from the specialist centre was at hospital B doing a clinic.

In the end, Norma was able to take Lana to see the specialist at hospital B rather than the local hospital. The specialist was not sure what the lump actually was but said Norma could ring him again if it did not improve. She rang him later in the week via his secretary and he asked to bring Lana to the specialist unit to be seen. Norma seemed pleased with the outcome and it was clear that she had used her knowledge of the systems to achieve the best outcome for her daughter whilst complying with the rules she had been given about access.

Norma: ...where normally I would have rang the specialist unit and said: "she's got this lump. Can I bring her in ? but I thought, no, I'll have to do it the proper way.

Similarly, Helen found that her knowledge of the hospital systems grew and she became very experienced and knowledgeable about them. She talked about her initial experiences in the hospital world first,

Helen: Totally overwhelming at the beginning, to start with very in awe of the consultants and the people there...

Helen: ...to start with I was totally out of my depth. I didn't know what it would be like at all.

Helen: sometimes the queues were ridiculous but I never minded because when it was our turn we got as much time as we needed and I never felt rushed. ...realised that if you ask for the last appointment you wait less time., they seem to catch up...it is those little things you learn as you go along - a good tip.

For Angela, who was a parent and a children's nurse herself it was evident that she already had this insider knowledge and although this had been gained through a different route to other parents she nevertheless utilised it in a similar way, for example, in navigating hospital systems. At the same time, however, the range of her clinical and insider knowledge brought with it some different worries as a parent. Whilst other parents felt concerned by not knowing information about what the next steps might be or the outcomes for a particular diagnosis or treatment: Angela was able to anticipate many more outcomes and think ahead a step each time which had advantages and drawbacks. An example of Angela's experience with her daughter, Louise, in the accident and emergency department showed some of the similarities and differences

between being an 'insider' and an 'old hand'. After taking a phone call at work Angela picked up Louise from school where she had felt unwell with chest pains and breathlessness after P.E. She took her to the nearest accident and emergency department to be assessed as she remained breathless and distressed. Angela felt very agitated and worried about Louise as she arrived in the department looking for a wheelchair to bring her daughter into the hospital from the car park. She was annoyed that the nurse on the front desk ignored her initially. Louise was later seen by a nurse practitioner – the transcript reflects the concern of the mum who was still trying to 'search for the clues' to determine the extent of the danger, just as other parents described. The difference was that she, similar to the regulars who had 'learned the ropes', had some additional knowledge and skills to help in her appraisal of the situation:

Angela: ... we saw a nurse practitioner there as well, erm, who thought because she had a wheeze – like, she was breathing with her whole... with all her shoulders and things and she had a wheeze as well, but it wasn't when you breathe out; it was when you breathe in, so I'd sort of thought: is it asthma; is it not asthma? Now this is a good hour and a half since P.E., so she'd been like this and she was quite distressed erm, and so the nurse said: Oh, I think it might be a wee pneumothorax, so we had to go to X-ray and they didn't let me in the X-ray as well, they said "Oh, you have a seat and I'll take her in" and I was like, you know... and I said "is that alright?" and they said "yeah, that's alright" and she's had an X-ray before, so she was alright. ...

I: Were you worried about her?

*Angela: Erm, I was a bit. I didn't think... for her breathing, you know, it did get easier, but I was a little worried 'cos she was quite distressed about it sort of thing. Erm, and I didn't know. I wondered initially if we would just get a nebuliser or something and go home, you know, but I was thinking: it's not when she's breathing out; it's when she's breathing in sort of thing. And when they said pneumothorax, **I was thinking: oh, good grief. Chest drain. Oh no.***

Whilst generally 'insider knowledge' may be viewed as advantageous as a parent in hospital it is evident that Angela's knowledge meant that once the nurse said "pneumothorax" she then anticipated the treatment and what that would mean for her daughter. This was a worse outcome than she had been anticipating so when she thought one step further ahead of the information she had been given by the nurse, she was more fearful.

New Parents - personal life perspectives and lens

Parents inevitably brought with them their own past life experiences, knowledge and beliefs which is referred to here as their 'personal life perspective'. This 'personal life perspective' determined the lens through which parents viewed and interpreted their child's hospitalisation. This influenced their expectations and provided some benchmarks against which parents compared any 'clues' they encountered as they tried to understand the world they had entered. An example of this was when Mary positively evaluated her experience in comparison to her expectations.

Mary: But he was actually great with her...I actually came out thinking that. I thought "Oh God", because you know sometimes...I mean I work

with people with learning disabilities and sometimes you take them into doctors and they're speaking to you and this person is sitting there and can't understand what they're talking about.....But he didn't , he spoke to her the whole time.

Some parents from the same family held quite different personal life perspectives and faced with the same situation with their child had different perspectives on this arising from their own 'lens'. Thomas's parents acknowledged their very different viewpoints. Gina explained that she realised that when she lived in her previous 'outside world' she had a particular view of health professionals and specialists as being the expert sources of knowledge. It was evident that she continued to adhere to her beliefs for a long time into the experience of managing her child's problems before she altered this view and appreciated her own expertise. Even across interviews, she had learned new things about her role and the professionals.

Gina: ...And also, I think, erm, you know, I'm quite naïve I suppose about the whole health service and expecting to go and them just to say "well, it's this and it's this and this is going to happen and we'll have to do this and we'll have to..." and they didn't. They just used to say "well, how is he?" and I would just have to say how he'd been and I was thinking well, you should know. You're the expert, not me. I'm just his mam, you know what I mean? Erm, and I think that was one of the hardest things, but I think I've got used to that now. Now I tell them and... and I think sometimes if they said... like, everything they said, I would do it religiously when he was tiny, like, you know "you must do this, you must do that" whereas now, if they say... particularly the dietician, she told us to do things and in hindsight, I wouldn't do it now. Erm...

In the above account Gina explained that as her views of professionals altered and she has realised that their knowledge was not unlimited and differs to her own as a mother. She now recognises that as Thomas's mother she has different knowledge to professionals and that she can adapt, modify or reject their advice when applying it to her child. Her personal lens remained unchanged for some time into the hospital experience but as she reflected and learned from different situations she moved on to a position where she recognised her role and ability to contribute to a partnership with professionals. This was perhaps a more extended journey than her husband David who had a very different personal lens from the outset.

Further examples of this difference between parents in how they viewed professionals was in the way they adopted the dietician's initial advice. Later the mum acknowledged that she dealt with professional advice in a different way now than she did at the beginning. But she was the one that had great belief in professionals' knowledge and not her own, whereas the father did not hold health professionals in such an exalted position as his wife. In the absence of professional knowledge held by medical and nursing staff the father used his own knowledge, applying logic and common sense to the problem. In a sense he was valuing his own viewpoint and weighing it up against listening to professional knowledge which did not appear to be solving the problem.

David: ... And the dietician's advice was like "fill his food full of olive oil".

Now, so we were doing that and I was thinking like... If you ever taste food with like, olive oil in, all the food tastes the same and it's just horrible and sickly and so... we had a child who was being sick quite often; who couldn't keep the food down and then you give him that, and his taste buds and he was just chucking up, like all the time and I actually think

that that made it worse, rather than better and it got to the point I was going: Gina. Stuff it. I've had enough of this; it's just ridiculous. I'm not having any more of it. You know, put sugar on...

Gina: But it was because they'd told us to do it. I was like "no, they've told us to do it..."

David: But it was like, you're just doing it literally, and months later, I was going: Gina, nah, stop. Because it was like: sugar, olive oil, sugar and I'm thinking: how can this be good? That's just saturated, you know, artificial weight gain, which is fair enough, but...

Gina: It's not solving the problem.

David: But it was just like: he's just chucking up and I'm thinking: how can that be good? That's actually a negative... it's actually causing the problem as opposed to helping. And then as soon as we stopped, his sickness stopped hugely. He's still being sick, now and again, but it wasn't like every single time like this, all of the time. He was still being sick quite a lot and it's only recently that he hasn't... that he has stopped doing that..

The rationale for this dietary advice was not clear to the parents and their compliance with it even when it did not seem to be helpful was fuelled by Gina's believe that professionals must be correct whereas David did not agree with this view point. In the interviews this was just one example of a situation where parents were acting on behalf of their child and trying to do the best for them to improve their quality of life. At times, as in this example, professional's advice

did not always fit with the parents' experience of the child's problem leaving the parents feeling they were on their own in finding a solution.

Another example of parental perspectives on health care was provided by Graham as he explained his expectations of health professionals.

Graham: This might be completely unrelated , but you know, one of my perceptions is that there seems to be a growing number of people that are getting more and more conversant with medical issues because of the internet and so they seem to be able to talk quite intelligently about various medical things that they might have, or other people might have and so on, and I'm just...well, I was going to say I'm not interested; I probably am interested; I just wouldn't do that, 'cos it's not something I would particularly think to do. I don't know if, it's in my head, I think: that's fine; if something's wrong with my car, you know, I'm not bothered, I just take it to a garage. Equally something's wrong medically, I might be more bothered, but I'll still just take it to the experts to deal with and so I am aware that that's probably my approach to it, almost like..don't bother me with the technicalities; just tell me when she is going to get better, how long this is going to take and so on...whereas I can think of a couple of friends and colleagues who I could imagine would have a very different approach; they would probably be wanting to debate the technicalities much more with the medical staff and so on, yeah.

Making sense of the clues - altering the lens

Parents came to this alien world with their own personal life perspective and lens through which they interpreted the world into which they had been plunged.

Parents on the journey from being new parents to old hands gained knowledge and experience which altered their perspectives and influenced their judgement of how best to protect and advocate for their child in this alien world. Some parents seemed alone on this journey and had made sense of the clues along the way and worked it out for themselves whilst others had an interpreter and guide to help them by way of the professionals who travelled alongside them. As parents made this transition from being new parents to old hands they decided how best to respond in this alien world and whilst their parental responses varied widely, their underlying aims were consistent - to protect and advocate for their child. Parents searched for clues often in a hyper-vigilant way to help them to understand how best to act in their child's best interests.

At the time of the interview parents were usually looking back on events and their 'at the time' interpretations were clearly modified over time with the benefit of the knowledge and experience they had since gained. The parents' narratives reflected not only their interpretations of the 'clues' they found - "at the time" but also their current understanding of events which had been altered through their own reflective analysis of what took place, subsequent knowledge acquired and experience gained. Parents often acknowledged that, at the time that they were searching to understand the situation, they themselves were in an anxious state and that their memories of the events might not be completely correct. However, there were particular details of events and their own thoughts and feelings in those moments that were recounted with more certainty. They also gave examples of how some of their responses to situations were different now to when they were new parents as their understanding and perspective altered as they became 'old hands'.

In other examples from the interviews parents recognised that there was information that they gained later that helped them to appreciate in a completely different way, the events that had occurred. Graham realised after his daughter's discharge how seriously ill she had been when they had first taken her to the hospital as an emergency. At the time he believed professionals knew what to do and handed over his daughter to them: they acted swiftly and she eventually fully recovered. It was not until much later, when he had learned more about the illness and the need for urgent clinical interventions that he fully appreciated that the staff had saved his child's life and how different things could have turned out.

Graham: ...being admitted to hospital with meningitis or meningococcal septic....or whatever it was. ...I think on that occasion, the staff could not have been more attentive and helpful and just treating the situation with a proper sense of urgency and professionalism and you know, and even at that point in time I was probably still not fully aware of the seriousness of the situation, so it was only, in hindsight, looking back at it that I think I've been able to piece it, all of that together and realise that, you know, how serious or potentially serious it was and how just thoroughly professional and what's the word, sort of "appropriately" that the staff responded to that.

I. yeah. I see.

Graham: ...I'm sure this wasn't the case, but I can almost have imagined them wanting to turn around and say "didn't that father realise that we've just, you know, saved his daughter's life or limbs or whatever", you now?

Another example of a change in a parents' perspective as they learned more information was Gina's experience. Earlier she described how overwhelming it was to see so many specialists soon after their child was born.

Gina: ...initially we were just seeing all these consultants and I think we said last time: that was the worst thing. Like you didn't feel like there was any continuity or any sort of like sharing of knowledge or anything and I think we were actually lucky. You know, because we went to the six weeks check and that was when the doctor said "Oh, we think there's something not quite right" and it was then he brought all these people together in one day for us. You know? ...obviously because Thomas was so different, which we hadn't appreciated...I went to this seminar thing - I think I told you about it - with the genetics people and it was genetics and how siblings were affected and stuff. And there were loads of people there who you know, they hadn't seen anybody 'til their kids were much older or something had happened and some of them had had to really fight to get into the system if you like. Whereas we were in the system from six weeks. So we've been lucky because we've had all of this expertise and all of this attention straight away and in that respect, it's good. You know, we see everybody. Whereas some people, even just seeing their own doctors, they've had to sort of more or less beg with their doctors to say "look, my child needs to see someone else to then get to see the specialist"...

Being alone or having allies

The feeling that parents were alone in interpreting and dealing with situations was something that several parents identified as being very difficult for them. In contrast, parents that spoke much more positively of their 'landing' and subsequent experiences in the hospital environment identified that they had been given support, information and explanations by staff. In this way the interpretation of information and "clues" was not something they did alone, they had a local interpreter (a health professional) who was available to help them to make sense of situations and to guide them. The sense of not being alone in their efforts to protect and advocate for their child in this alien world appeared to have a very reassuring effect on parents and influenced their judgement of the quality of the care provision.

This extract is an example of how Graham felt when he was waiting for his son to be assessed who was suffering with abdominal pain.

Graham: I think all of the positive experiences I've had, have been, you know, both the kids being born in hospital and Louise's meningitis and appendicitis and so on, and I guess those are all situations where you know, the person in question is being looked after and I think I suppose the contrasting thing was with Jonathan, where he wasn't being looked after and I was having to look after him ...you know, what I really wanted was the experts to intervene and make everything okay, sort of thing, or at least, ...no matter how ill he may or may not have been, at least getting -you know, that he was in the right place, getting seen to, getting

the best care and so on and the fact that we weren't able to access that was sort of what created the stress really.

He went on to explain that, although Jonathan turned out not to be seriously ill, he remembered this hospital episode as being the most stressful, despite previously staying in hospital with his daughter when she had meningitis and appendicitis.

Graham: ...because he wasn't being looked after and wasn't in the hands of the experts, it therefore became more stressful.

In situations where parents perceived that they had received little or no communication from professionals they felt they were on their own in deciphering the meaning of what they were seeing and hearing around them. This was particularly frightening for parents when they sensed danger in the situation for their vulnerable child but did not have anyone to interpret the situation for them. This uncertainty and "not knowing" was described by majority of the parents as the worst part of their experiences.

This extract is an example of parents feeling alone and without such an interpreter -

David: ... it was like being faced with ten doors and then somebody would open this door and then come out and speak to you and go like "oh, right" and then they would go away and then two doors would open here and you were going, speaking to them obviously and they would say "so what's the problem?" and you would go "oh, well this and this and this" and then they would go away, but there was nobody in the middle saying "actually, what's the strategic look?"

Gina: Erm, but I think for me, that was one of the most difficult things, 'cos you would go and see a specialist and obviously they would tell you about their little bit, but I always think, but how does that fit with everything else?

These parents felt alone in trying to piece together the whole picture of their child's problems as individual consultants assessed and gave opinions on their specialist aspect of the potential diagnosis. Without someone to draw information together and explain the relevance of each specialists input the parents felt alone as they continued to worry and live with the uncertainty.

There was a real sense of parents needing someone to help them by providing information and explanations, in some cases their feelings of being alone were further exaggerated by being physically left alone. Examples include, being left alone with their child in a room with the door shut or where there were no windows in the room or when there just did not seem to be any staff presence.

In this example, parents felt alone in the situation because of lack of information and explanation along with being physically left alone in a room. These feelings seemed to further remind them of their distance from their extended family support leaving them feeling even more isolated.

I: What do you think could have made that a better experience?

Brian.: Maybe not being left, I think... And it might not have been for long; I can't remember. I don't think it was even long. There was a nurse kind of hovering, you know. .. But maybe just more of a presence, I think. but the thing is, we're not from here either and like, other people could

*come in with children, would have their whole family sitting in the waiting room and we didn't. **It was just us; there was nobody else.** I mean, there is, but they're miles away.*

The physical and visual reminder for these parents that they were alone in this frightening situation seems to echo the father's feeling of being alone in trying to interpret the doctor's words and dealing with the experience. This notion of being alone or not being alone in facing these dangers was something that later influenced parents' judgements of the quality of the care.

In another example, David recollects the frightening experience of watching his baby being born and then realising that something was wrong and not feeling confident about the actions of the staff. In the absence of anyone to explain to him what was happening he watched and worried about his baby. It is clear from his story that not knowing what to do or to think about the events was very anxiety provoking. He felt he was reliant in this situation on professionals to help his baby but their actions did not instil him with confidence and in the absence of anyone to interpret for him and reassure him about what he was seeing and hearing he continued to feel very frightened.

David.: They kept putting the oxygen thing on [pulse oximeter] they put that in maybe two-dozen times; they just couldn't get a measure; it was falling off and it was this, that and the other and I was looking at it, thinking "what's going on?" and they were just... it just looked like incompetence. You know, I don't know if it 'cos he was little, he was weak and everything else, and they just couldn't get the measurement; they just kept trying it again and trying it again and then going away and

then trying it again and it was like... and they never got the right measure. They never got a measure that was acceptable. It was just like "oh, that's not the right measure. Try it again... get another one..." You know, blaming the kit, rather than actually thinking, actually, it's right.

*... Well, I just knew there was something wrong, but I just couldn't articulate it or whatever, because you just keep thinking, well, **you cannot say: "I don't know what to do"**. You just knew instinctively there was something wrong.*

...And there was no communication. The communication was absolutely appalling. It was just like, while you were standing there watching and observing, thinking like, crikey, I am not confident in what you are doing, 'cos I don't think you know what you're doing. And the kit they had was... it just seemed flimsy and useless. It was like some sort of like strap thing and it was just... like for a little... like, using it for any baby would be... it didn't seem like very good kit actually; it seemed very archaic.

In contrast to David's experience, Graham acknowledged that his wife Angela would explain clinical information for him later if he did not understand it: in a sense he had his own interpreter so had less need to rely on clinical staff.

Graham: I think for me, quite often, if I just wasn't following some conversation, I would just think: well that's fine, 'cos I'll just get Angela to explain it to me, you know?...so, I would not necessarily switch off, but you know, would just think: right, I don't need to understand this, because Angela will explain it to me later...I can't think of different things that were said necessarily , but you know, scenarios and situations where there would be some doctors or nurses would be giving us some information

that really meant very little to me, I would just think: I will get Angela to explain it to me later.

Parents viewed the clinical expertise of health professionals and treatment interventions offered by the service as critical to protecting their child from the dangers their illness or injury posed to their child. Provided their child obtained access to these, parents were generally tolerant of almost any other aspect of the service or the staff. However, to go beyond this critical satisfaction level there were a range of clues that parents identified as a means of recognising high quality care. In analysing these clues it became clear that these examples centred on when parents had felt that the professionals had acted as their allies: protecting from danger and advocating - specifically for their child. The important words here are 'their child' as the examples mainly focussed upon interactions where there was recognition of their individual child and family's needs rather than having to fit in with the system. The clues were identified in a number of sub-categories in the data - the person versus the system; going the extra mile; bending the rules; seeing the child and the family. In all of these sub-categories there were examples where the parents had noticed clues that made them feel that professionals were their allies in making sure that their child was safe or in ensuring that they were advocating on behalf of their child and family. The following extract is taken from an interview with Wendy who felt that her child and family had high quality care; effective communication and good support from all of the staff.

Wendy: They were all brilliant and they all, erm, answered every question that we had, and like, we were asking stuff like "what's it going

to be like in the future? What's the sort of side-effects or complications?"
they answered everything straight and were really good and helpful. And
I mean, after the hospital we've had the dietician, the diabetic nurse and
they've like been in phone contact all the time, so even , when we've left
hospital, it's been great, because we've had the support. ..

I think they accommodated us as well. I mean, like, on the night time,
they were finding us beds, even though it was like 1am she was finding
us a pull out bed..like comfortable beds rather than a chair. And like
going that extra bit.

Another example where parents felt professionals were their allies was given by Gina, mother of Thomas, who recounted that when they had reached a point where the diagnosis was no longer the central focus for them, she was pleased that the specialists were, on her child's behalf, continuing to share information internationally looking for an answer to help in the diagnosis, treatment and management of Thomas's condition.

Gina: But yeah, as I say, as time's gone on, the geneticist thinks that
they will find a diagnosis for him, but when we go there, they take
pictures, photographs and look at his hands and erm, and they've said
that they're going to take that... they have this clinic worldwide, where
they take...

I: Right, so they share information.

Gina: Yeah, share information. Which, again, I think for us, it was, it was just like a new world.

There is a sense here of professionals being allies to the family as they continue to search for a diagnosis on an international scale. This is in stark contrast to earlier comments of how it all initially felt for the parents as they saw a range of specialists.

Gina: And although we were seeing Dr. F, who was the paediatrician at the hospital, it wasn't really until we got into... when Thomas was a little bit older, we now have a community paediatrician, who we see at home, where... I mean, I'm saying she's pulled it more together now; I don't know whether that's right, or whether we just got more used to dealing with different people.

I: Right.

Gina: Erm, but I think for me, that was one of the most difficult things, 'cos you would go and see a specialist and obviously they would tell you about their little bit, but I always think, but how does that fit with everything else?

The most positive experiences that this family related about professionals working together with them for their child's sake was from the education setting. In this situation rather than feeling alone to guard and advocate for their child they felt they had allies as all the professionals met with the parents and Thomas at the same time.

Gina: And when we got there... erm, because again, you never know what to expect, erm, when we got there, the dietician was there, the

school nurse was there, the speech therapist from school was there. Me and Thomas, and that was brilliant.

I: Oh, right.

Gina: Because like, you had the speech therapist who's working with them all the time – and they do these food groups and things in school and then, again, the erm, you know, the school nurse, so she, like, they weigh him and like, do his height and that all the time, and then the actual dietician, and I thought that was much better, 'cos it was looking at the whole issue, 'cos I never really used to associate speech therapist with dietician and eating, you know...

I: Yeah, but it's all the mouth and...

Gina: Yeah, exactly and chewing and stuff like that. But I thought that was fab; I really did. And again, now we're in the school system, there's a lot... we go and see the community paediatrician there now as well and there's a lot more coordination. But again, it's probably different ages and a different system.

I: so all the experts in the room together? looking at the problems as a whole.

*Gina: Yeah. Yeah. **And I mean, you know, if you step away from it, you think well that makes sense.***

The parents had thought about why this felt so much better to them and how this would be great if this could happen in health care too but they said that they understood the difficulties in achieving this in hospitals. They seemed to feel

that this did not happen in health care as they had only experienced this type of collaborative working with the family in education settings and not in healthcare settings. They assumed that given their extensive experience in a variety of different departments within the hospitals that this approach to care must not occur anywhere in the health service.

When recounting her different hospital experiences with her son, Helen, explained how the practices varied across services from the intensive care unit, children's wards and prosthetic clinics.

Helen: very senior people [in intensive care unit] but very accessible and very keen to communicate with you and they use to take us in the room to talk , very frank and honest so kind of learnt to trust them, they said it how it was, I don't think they beat around the bush in there and witnessed some tragic things a child next to Justin..... a young mum lovely girl, but they are very honest with you so you trust them. The further away you got from intensive care the more variable the practices become...

At another point in the interview, Helen explained how it felt in the initial days of being in intensive care with her young baby. She felt the team around the family were very supportive and provided expert care for the whole family and then an incident occurred which was very distressing for her.

Helen: one night a young doctor wandered in when I was on my own with Justin and up to then we had been getting through each twenty four hours and then the next were critical and we were starting to feel we were out of the woods a little then, he started making comments about if this happened or that happened what might happen and I was in a

terrible state and Russell was not there that night for some reason but the sister came and spoke to me on my own later and said ignore that man...

Although the staff in intensive care unit had been frank and honest with Helen and Russell from the beginning they had developed a trusting relationship with the parents. The parents felt the staff were alongside them in their experience and it seemed that this doctor intruded into this discourse to some extent.

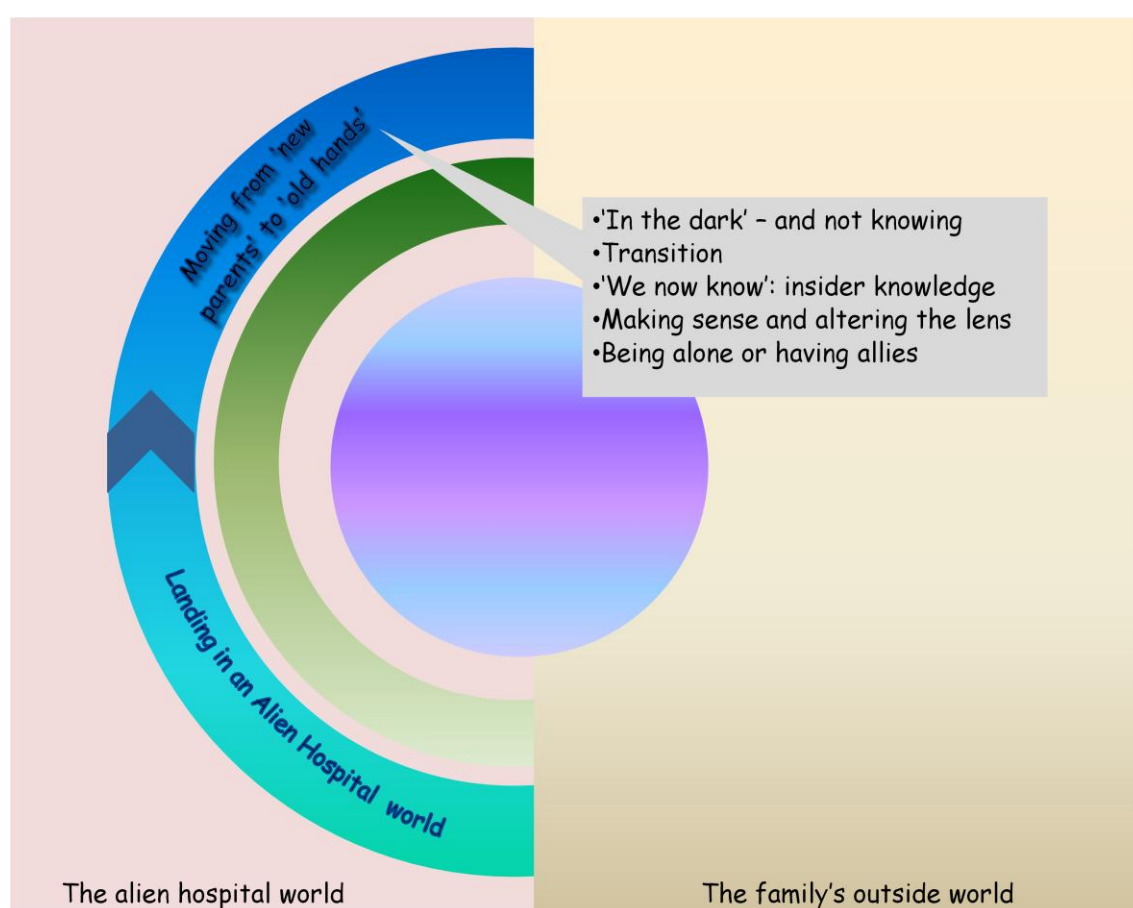
Conclusion

The findings presented in this chapter highlighted parents' journeys from being in the dark and not knowing the hospital world to becoming old hands (see Figure 5). The personal lens through which they viewed this world altered as they became more familiar and knowledgeable about it. From parents' accounts, there is a real sense that they needed good quality, consistent information to be effectively communicated to them throughout their hospital experiences with their children. When information and explanations were not provided, this added to parents' vulnerability and anxiety leaving them feeling alone to make sense of the situation, evaluate the potential risks and outcomes of their child's illness for their child and family (see Figure 5). Parents wanted someone to act as a key contact for them to co-ordinate care and help them to interpret information and their surroundings is also evident in the narratives. For parents these were key concerns and the extent to which professionals fulfilled their need for information, provided with meaning and with explanations of the possible next steps or outcomes, was central to their judgements of the

quality of care. At the same time, their feelings of either having allies or being alone in their experiences also determined their assessment of the quality care (see Figure 5).

In the next and final findings chapter, the way that parents make judgements about quality is presented and their responses are explored. The parents' views of complaining are demonstrated within the discussion and the factors controlling some responses are unpacked.

Figure 5. Moving - from being 'new parents' to 'old hands'



Chapter 7 Findings: Parental judgements and responses

Introduction

In this final findings chapter, parents' recollections of the way in which they made judgements about their experiences and responded to any issues of concern to them, are described. The complexity surrounding complaining as a possible parental response is highlighted in the parents' narratives. Finally, the factors identified as influencing the variance between the 'at the time' and the moderated and more positive 'on balance' judgements become evident. In this chapter, findings are presented using the following sub-headings:

- *Judging the clues*
- *To say or not to say*
- *Thinking something*
- *Asking or mentioning something*
- *Saying or doing something*
- *Complaining*
- *Judging the quality*

Judging the clues

Parents searched for 'clues' to help them to understand the strange world in which they had landed and to determine how to best respond to it. The searching, interpretation and responses all occurred within the context of their child being ill, injured or diagnosed with a health problem. The combination of heightened parental emotions and fear as their child needed hospital care left many parents feeling vulnerable and anxious. Parents often described not

knowing what to do or how to cope with this unexpected situation as they struggled to understand the world they found themselves in along with its unknown dangers.

At times parents talked about the situations as if they were almost back 'in the moment' and some of the memories triggered emotional responses in them as they were reminded of that time. This gave an immediacy to their accounts and appeared to be descriptions of the moments that linked their chronological past to their present and possible future. Parents often were very clear and detailed in recounting their experiences, particularly when the described event was a significant or emotional one for them, but acknowledged that they could not remember many of the other pieces of information about what else was happening at the same time. At the time of their hospital experiences, parents needed to make judgements, not only about the potential dangers for their child, but also about the staff and the service that were being provided. These initial or 'at the time' judgements were almost unconscious evaluations of the situation that triggered certain emotions and prompted an automatic or immediate response.

Parents made observations of the encounters or have emotions and feelings evoked by the experiences that they then evaluate to provide their overall assessment or judgement. Parents used the "clues" to build up their picture and assess the situation. Many parents spoke of the strange and unfamiliar environment of the hospital when they had not experienced this before or if they were recounting an early experience of hospital. In addition, they described situations where they were trying to make sense of what they were seeing and hearing with their limited knowledge of this new and unfamiliar territory. It seemed at times that they were in the dark searching for information to help

them understand and cope with this new and frightening even potentially hostile environment. Sometimes they tried to apply logic and knowledge from the outside world in which they normally lived to try to make sense of the situations they found themselves in.

When parents were asked about positive and negative aspects of the care experiences they would talk about these 'clues' by way of a story to exemplify and explain it and then later in the interview their evaluation of the overall care would be given. Judgement of the clues appeared to alter over time as the parents moved from being new parents to old hands or as they moved away from the event under appraisal. This may explain the repeated way that parents recounted events which they rated as very poor quality 'at the time' and which evoked strong emotions as they relived them but then later in the interview the overall assessment of their experiences 'on balance' was usually much more favourable.

During the interviews there were numerous occasions where parents were relating to me examples from their experiences to illustrate to me the "clues" that they noticed that made them feel this was very good quality care or very poor quality care. There was a repetition of certain words in their telling of the story which on further analysis relates to how strongly the parents felt about the clues at the time of the incident. For most parents initially their assessment of the situation caused them "to think" something was good or poor, in some cases these thoughts were almost conversations with themselves.

Parents used their insider knowledge or 'now known' knowledge to help them to respond in ways that they believed was the best approach to gain what their

child needed - to keep them 'safe' and to advocate for them. As parents became 'old hands' they acquired more experience and knowledge that helped them to control the elements of the experience that they could anticipate and control. This knowledge and experience helped them to adapt to their situation but they also used it to guard and advocate for their child more effectively. The parental responses to situations depended on a range of factors including their own experiences, personalities and beliefs but regardless of how different their approaches appeared the purpose was always the same - to protect their child from dangers and/or advocate for their child.

To say or not to say

When parents had a concern or a query from their monitoring and search for clues, they identified a range of ways they dealt with this situation. Parents described responding:- by thinking, asking, mentioning, saying or doing something. Some parents also used non-verbal signals to show their dissatisfaction or concerns, for example, facial expressions or silence. Their explanations for their chosen responses shed some light on the way in which they made their judgement of the clues they had found and how they weighed up their options, deciding upon their best response at that time. Parents were constantly trying to make sense of all that was happening around them and this was often a constantly changing picture. The way that health care professionals communicated with the parents influenced their interpretation of the information and ultimately was able to alter their personal lens positively or negatively. The professional was in a position to act as a type of translator for the parents in this unfamiliar world, making the parents feel they had someone

alongside them to help them in their search for meaning from the clues around them. However, the lack of a translator often resulted in parents feeling they were left to work things out for themselves. Their personal lens influenced their responses and their lens continued to change as they moved along the continuum from being a 'new parent' to an 'old hand'.

Thinking something...

Whilst 'thinking something' at the time of their query, they did not necessarily voice these thoughts to others or to the health care professionals. These thoughts were the parents' interpretation and evaluation of the clues they had noticed and they were almost keeping a mental note of these as they built up their understanding. Sometimes they went on to ask something or mention something to the staff as a way of checking out their own interpretations of the clues they had gathered but also as a polite way to raise an issue with the health care staff. Asking or mentioning something both appear to be ways of raising a query with the professional without it sounding as if the parent thinks they know more than the professional - there is almost an observance of some unwritten rules regarding the relative position and power balance between the parent and the professional.

Wendy: . Dawn did have one nurse, during the night, who was getting her insulin and it seemed, her attitude, as if she's never dealt with kids before. And she wasn't bad, but she was just very blunt and straight to the point and I thought: you shouldn't be like that...that's the way you speak to, like, an adult; not an eight year old.

Where there was a lack of interpretation of information by professionals for the parents they were left to draw their own conclusions. This brought with it the potential for misinterpretations of the 'clues' and unnecessary parental worry brought about by being left alone to work it out for themselves.

When Thomas's father spoke about his birth he recalled how he was thinking at the time and then later how he had thought about the causes of his child's learning difficulties and had tried to work out whether different actions at the time of the birth would have altered this situation. As a mother Gina had undergone additional tests and although some blood levels had been slightly raised the message they had received from the medical staff was that this was not too worrying.

David: ...but they weren't overly worried, so when it came to the birth, we were expecting everything to be okay, with a little few caveats, but like... but then he was born and then the... I just knew something was wrong and I don't think he... I don't think he erm... I don't think the nurse or the doctor really sort of like had that feeling, you know? And I just kept thinking like, there's something wrong here, there's something not right. I don't know what it is and like, 'cos obviously your brain's going like 100 mile an hour and you think there's something wrong, there's something just not right, erm, and they tried to keep giving him like little bits of oxygen... and they waited a long long time and that was... and you start thinking like... and they ended up putting him into, like, intensive, you

know, to get his oxygen levels up, but it was some hours later and you just kept thinking: "could something better have been done there?" I think time wise, absolutely, but would it have made any difference to his brain? 'Cos you start thinking well... but then I sort of keep thinking well actually, thinking about it, well, if he had no other thing wrong with him, you may come to that conclusion. However, you're going like, well actually, he's got a fused kidney, his eyes, and you start to think well, possibly not, it's part of his condition... you know what I mean.

I: Right. Yeah. It would have happened anyway, wouldn't it?

David: You know, if you try to do it on balance of probabilities it was an oxygen deficiency. If you... I don't know. That's just the way I'm thinking; that it's actually part of his undiagnosed condition. Aye. I just don't think it was managed very well. At all.

Gina: But at the end, I suppose they were just looking after the baby, because they were obviously...

David: Well they knew. They kept putting [something about oxygen in the blood] they put that in maybe two-dozen times; they just couldn't get a measure; it was falling off and it was this, that and the other and I was looking at it, thinking "what's going on?" and they were just... it just looked like incompetence. You know, I don't know if it 'cos he was little, he was weak and everything else, and they just couldn't get the measurement; they just kept trying it again and trying it again and then going away and then trying it again and it was like... and they never got the right measure. They never got a measure that was acceptable. It was just like "oh, that's not the right measure. Try it again... get another

one..." You know, blaming the kit, rather than actually thinking, actually, it's right. There's something wrong here.

The father's helplessness and worry is evident in his words as he watched the staff repeatedly try to measure the baby's oxygen levels. He recalled there was no communication with him to explain to him or his wife what was happening so he watched and interpreted the scene for himself. His interpretation of the events he witnessed were that there were numerous attempts to use a piece of equipment to gain a reading on the baby but that they kept having to try again and using his knowledge and experience of the outside world he could not understand why the equipment appeared to be so "archaic" and not fit for purpose but also why, if the reading was poor why they were not acting on this reading rather than repeating the reading, he assumed and he felt this was because they were blaming the equipment. He also thought that if the equipment was not working properly why had they not found a different probe. His observation was that he was worried but the staff did not seem to think there was anything wrong. Even later when the mother and baby were moved on to the ward he felt there was something wrong. Of course listening to this recollection one can wonder if the staff were worried about the baby but were trying to appear unworried for the parent's sake and the repeated attempts to record an oxygen level could have been repeated readings been taken to measure the response to their interventions - perhaps oxygen administration, drugs or fluid being administered. The sudden transfer of the baby to the high dependency unit also seemed to occur without full explanation to the parents who were again left to interpret this situation for themselves.

Although the father spoke of thinking these things to himself at the time and later he continued to think it over, but he had not discussed these matters with the staff. One of his worries was that his son's learning difficulties may have been caused by lack of oxygen or brain damage at birth and if the staff had acted more rapidly would his son still have had a learning difficulty. Over time he deduced for himself that as Thomas had other physical problems that he was born with, it was most likely his learning difficulties were part of a syndrome that he was born with rather than an accident at the time of the birth.

A further example of 'thinking something' but not voicing it was provided by Gina -Thomas's mother. This related to her experience after Thomas's birth when she was visiting him in the HDU.

Gina: ... Erm, and then I remember, I was going round, I was like wheeling and... I can't remember; it was in HDU, but I was allowed to bring him back after a while, and they had to take him back for like antibiotics and I was wheeling him round myself...

I: After your caesarean.

Gina: Yeah, and I mean, luckily, I was alright, you know, erm, but I was thinking: "I don't think this is quite right". D'you know what I mean? ...

Whilst she thought to herself that she perhaps should not be wheeling him back and forth from the unit on her own, in terms of his safety and her own, she did not voice these thoughts to the staff.

Gina later talked about the follow up appointments for Thomas when he was a baby. At this stage the parents were still very focussed on having a diagnosis for Thomas although later this became less of an important issue for them. The communications that occurred during these appointments made Gina think about why she was being asked some of the questions. The responses of the specialist did not reassure her but just continued to make her think about the significance of the questions. It was not until much later that when she had more knowledge that she was able to look back and see that whilst there were some things that the doctors did not know and therefore could not tell her but there were also ways they could have prevented unnecessary worries by asking questions without explaining the significance to her. In the interviews there was a sense that the parents were left alone to interpret the questions and answers without someone making sense of it all for them. This was also re-iterated by the father when he talked about the experience of seeing the different specialists and it feeling to him that they were all coming out of one door after another and telling them their piece of information from their specialism but there was no one there to pull it all together for the parents and they were left to try to interpret this for themselves. This theme of being on their own rather than with someone in their attempts to make sense of this world are found in several parents stories.

The unspoken thoughts of the parents were interesting as they gave an insight into their observation of the situations. Angela provided an example of this when she talked about the communication of a doctor with her son aged 11 at the time of the admission. Jonathan had made quite a lot of noise in the waiting

area as he was bored and fed up with waiting to be seen. At one point he had become quite angry and loud in his remonstrations to his mother about the lengthy waiting time - to the point where she moved his wheelchair away from her to show him she was annoyed with his behaviour. She thought that the junior doctor who was sent to take Jonathan's blood after this may have thought he was going to be a difficult young man to take blood from so came in ready for this situation. She thought his approach was not very helpful but ultimately it did not create a problem and the bloods were taken. Whilst this is an example of thinking something but not voicing it this is also an example of a brief 'at the time' judgement which later the mum was able to set in context to make a more balanced judgement which took into account the fact that there was no harm done by the comment, it did not affect the outcome and there was some acknowledgement or tolerance that her son's earlier behaviour may have impacted on this junior doctor's approach.

Angela: But the bloods... I'm trying to think about the bloods. The doctor came down and said erm "Now I take blood from babies much smaller than you all the time and they don't make a fuss." I was thinking: what are you telling him that for? It makes absolutely no difference to him. Ha! So if I make a fuss, I'm not as good as a baby? But I mean, he was absolutely fine about it. And then we had to go back and see the doctor the next day and he was a bit better but not completely better. Erm, and he did say we'd have taken him in if he hadn't improved at all, so I was getting a bit worried about him.

Whilst parents may have thought that something was not very good about the care or the service they often did not voice their thoughts at the time instead

they remained fixed on the best course of action to protect and advocate for child.

In this example, the mother was annoyed at the response of the triage nurse in the accident and emergency department to her when she arrived with her daughter who was breathless and distressed. However, she thought this but did not voice this as she was fixed on the best course of action to ensure her child was safe. This triage nurse was literally the gate-keeper as he had to physically let her through the doors as well as through the referral system for assessment. This mum chose not to voice her annoyance about the nurse and chose a strategy that would enable her daughter to quickly access the assessment and treatment she needed which required the triage nurse to allow them through the door and through the referral system. This was felt to be the best strategy to gain what was needed for her child and the quality of the care by the triage nurse was seen as poor by the mother who 'at the time' judged the nurse as not been very responsive in assisting her as she tried to protect and advocate for her child in the emergency department.

Angela: ... there was the two receptionists and the triage nurse and there was queues of three or four people at the two receptionists, so I thought I'll go and ask the triage nurse and I knew I looked agitated and I thought: well that's good; I might get attention quicker, but as I say, he just didn't look up at all, although I was aware I was hovering over him, you know, I was deliberately trying to get his attention, erm, and as I say, I obviously looked a bit uptight, 'cos as I say, other people were sort of glancing over and seeing me, sort of thing, so... and he just didn't look up at all, he put his hand up and said "two seconds" or "two minutes" or

something. I think it was "two seconds" er, and then he said "what is it" and I said "I'm just looking for a chair; I've got my daughter in the car" sort of thing and he said "alright, I'll let you through" you know, and he let me straight through sort of thing, but there was just no chairs available and I just thought: you know, if you've got somebody you're bringing in who is ill...

An example of non-verbal display of parents' dissatisfaction was evident when Brian explained:

Brian: ...he was definitely dicing with death that doctor...I could have..I think my wife knew as well 'cos I just went really quiet, silent. I just thought "gosh, you better buck your ideas, pal, 'cos I'll have you on toast."

I: Do you think he knew you were upset with him?

Brian: He might have 'cos I didn't see him again.

Whilst parents often thought something about the care, this frequently remained unspoken though at other times their queries and concerns were verbalised politely but this was often done with caution. In practice a greater alertness and sensitivity to parents' signals that they have queries or concerns would enhance inter-actions. There is a need for professionals to check out with parents that the information and communications provided along their journey is clear and understood and that the opportunity to ask questions is offered.

Asking or mentioning something...

Where parents decided to 'say something' or 'do something' about their query this perhaps indicated that they felt this query needed a more direct or assertive

approach. At the times when parents decided to say or do something they usually wanted to signal to the professionals some level of dissatisfaction and were looking for something to change as a result of these responses either for their child or for children in the future. Even when parents felt that saying or doing something would have little impact on the situation some felt obliged to voice their concerns as their child's protector and advocate. Whilst both actions are still considered a step away from an actual complaint the parents did consider the consequences of such directness and for some it could be viewed as risky as they balanced up the benefits and possible negative consequences of their actions.

Angela: "well, you don't want to get the staff's backs up" .

Parents using a more direct or confrontational approach seemed to do so for the same reasons as the parents who used more gentle, passive or strategic approaches i.e. to protect their child and their best interests. Despite the wide variation in their strategies fundamentally parents believed that their approach would yield the best outcome for their child within this alien world. Sometimes the deliberations about what to say or when to say it, in itself, caused stress for the parents who felt a responsibility to say or do something if they believed it necessary for their child's sake.

In other situations parents who found themselves unhappy or dissatisfied either asked a question of staff or mentioned something to the staff rather than making direct comments. Posing a question to the staff or just mentioning something during a conversation was an early signal from parents that there was an unresolved query or that they were dissatisfied or disgruntled with a situation.

In recalling these instances parents inferred that if they were dissatisfied or disgruntled it was also their tone and non-verbal behaviour that accompanied their questions or comments that should have sent a fairly clear message to the member of staff that the parent was unhappy about something. Parents also used non-verbal signals to show their feelings to staff as a means of alerting the staff to respond to them without them having to say something direct to them.

By asking a question of the staff rather than complaining or commenting directly on the situation the parents did not directly threaten the power relationship whereby the staff are acknowledged by them as remaining in a dominant position of control. Some examples of this questioning approach by parents is passive aggressive in nature, others are asking permission for something and some are phrased as an enquiry. All of these approaches were ways of sending messages to the staff but some were more direct than others.

Gina, mum of Thomas, who has a learning disability, a complex medical history and has had frequent hospital visits was attending the hospital as a day patient for a planned investigation. Everything was going well from Gina's perspective until she realised that the staff did not have his medical records. Here she describes how she reacted:-

Gina - "...So we went and it was fine and then it was just probably a student and we went in the little room and she asked us some questions and she just said "is there any medical history" and I just... me face must have been a picture. Erm, and I just said "yeah". I said "have you not got his file?" and she said "no, we haven't got the file out". I said "okay then, where do you want me to start, really?" And I started reeling off, you

know, different things and she said "oh, it's okay, we'll get his file" erm, so that was okay..."

It is interesting to note that at this stage Gina had been in and out of hospital with Thomas a number of times for various investigations and interventions. Gina had initially been very compliant with health care professionals as her beliefs were that they were the experts but frequent experiences with the service had altered her position as she realised that as his mum she knew him best and also altered her views and also her responses to them. She had moved on the continuum from being a new parent to an old hand and her personal lens had been altered by her experiences. In moving along this continuum some of the hospital processes that may have previously felt intimidating and engender feelings of vulnerability in her were now very familiar and were not seen as threatening. She had been through the history taking process of assessment many times before and was frustrated with the necessity to keep recounting the details when she thought they should have read his notes and felt confident about her viewpoint on this.

Mentioning something...

Parents talked about how they mentioned something in consultations with the doctors or in passing to nurses who were caring for their child. This approach was used to indirectly raise a concern or draw attention to an issue that they felt had not been acknowledged, noticed or addressed by the professionals. Again, this way of raising these issues appears to be quite a gentle approach almost as if the parents are not wanting to question the professionals skills and knowledge or suggest that they may have missed something.

In one interview Thomas's father talked about a problem that was uppermost in their minds at that time and had been a long standing problem for Thomas. They felt this issue had never really been fully addressed or explained by the medical staff.

David: he eats – he eats hugely now. Like unbelievably how much he eats. Well, it's quite a good diet I think he's got. Erm, but there is certain things he doesn't like, but I think it's more textures rather than anything else, erm, but his movements, like bowel movements are like, just erratic, you know, like from an enormous number per day, you think: why does that happen so erratically.

Gina: Aye. He gets changed about ten times per day. You know; his nappies. Like, passing solids.

David: And sometimes, he's just like: all the time and you're just like: I cannot believe it and you just think: well, why is it like that some days and then not the others and then back again and you think like, there's something wrong there. And to me, that is like why: weight, height, everything else... it's the start of the mechanism, so there's that... I've never even really heard them talk that much about that and I think it's a real key to the problems.

*Gina: **We mention that every time we go as well.** Like about his digestive and his pooing and everything.*

The father had previously said that he thought one of the main problems was a digestive system problem for Thomas and it is evident in this excerpt from the transcript that he is again trying to make sense of these symptoms with the

knowledge he has and applying logical thought to the situation. They sound as if they are alone or feel alone in their interpretation of this problem and any possible explanations or solutions. Wearing a nappy and having erratic and sometimes frequent bowel movements was becoming more of an issue as he was growing older and it was restricting his activities.

There is an opportunity for staff to recognise that when parents just "mention something" this should be a signal of concern and staff need to recognise and respond to these signals.

Saying or doing something

Voicing their thoughts directly and "saying something" was an option that some parents chose. 'Saying something' sometimes came after a number of earlier signals of their concern had gone unrecognised or unanswered or was used when they decided this was the best strategy or only strategy left - or they had plucked up courage to do so. Converting their unspoken thoughts about something into a direct communication with health professionals required parents to decide this was a necessary step. An element of courage, determination and deliberation are noted about the times that parents recounted they had "said something" or had thought about saying something. There is a sense that whilst initial concerns over something may be overlooked or forgiven by parents, persistent or recurring issues lead parents to almost brace themselves to say something taking due consideration of possible consequences to them and their child of this action.

An example of this was seen when Gina, Thomas's mother, recalled the day that she finally voiced her previously silently held thoughts at an out-patient appointment. They had worried for a long time that their son would not grow properly in the future as the specialist repeatedly talked about his short limbs and measured them at each appointment. This worry remained in their minds for several years. Although there was a continued worry and uncertainty for the parents about their child's future, over time, they could see that he was actually growing and developing into a lovely little boy. However, at the time, this was a source of much distress to them and caused the mother on one occasion to actually ask the doctor if he was withholding information from them.

Gina: But I remember at one point... he's got a file like that, as you can imagine, and I remember, after... I can't remember how many... how long it was, but I got to the point where I was thinking you must know and you're just not telling us...you know? And this was all in the first year: 'cos this was the most traumatic. And I said to him at one of the appointments: "is there something you're not telling us?" and he said "There's the file; everything I've said is in this file" and I said "okay, well I just had to ask the question"...

Parents clearly deliberated and then made decisions about saying something to professionals but this was still considered a step away from a complaint. There were also examples of parents deciding that they needed to do something about their queries or concerns. An example of this was when Gina and David were struggling with the dietician's advice to mix olive oil and sugar to food for Thomas to help manage his digestive symptoms.

Gina: Thomas has got a problem with like he poos all the time, erm, and every time I go [to the hospital] I've said this since he was born and I just feel like nobody's really listening to me and every time I go I say about him pooing and we saw the dietician at Christmas, 'cos when he was little, we used to see a dietician quite regularly, erm, again, I felt like that was probably one of my worst waste of times and I just sort of stopped. Well, I just never took him anymore... 'cos he used to be sick all the time and in hindsight now I just think his stomach wasn't ready for food you know.

Gina realised that the dietician's advice did not help Thomas, but she complied with the treatment for some time and repeatedly told professionals about the problems. It was some time before Gina decided to stop complying with the dietician's advice and stopped attending the dietician's appointments. The decision to "do something" came about when Gina felt she had not been listened to when she mentioned or said something about the problems these suggested remedies were causing..

Another example of parents taking action when they felt dissatisfied with care rather than making a complaint was given by Helen when she recounted how disappointed she had felt with senior staff who provided the prosthetics for Justin. She did challenge individual staff when she felt unhappy with their assessments or advice but when nothing changed she chose to find a way to transfer this element of his care to a different provider outside of the region.

Helen: The Consultant was just dire. He was an absolutely useless man. He use to look at Justin, he would be about as close to him as I am to the telly [across the room] and he'd go "I don't think he needs any new

legs, he looks alright to me" and I would say "do you not think his feet are tiny for a boy of his age". So I got my confidence a bit earlier with him [laughs] 'cos I didn't think he was very good so then I started saying "well, I don't agree with that". .and we actually, for the prosthetic side of things we moved away from Central hospital to another centre 'cos someone told us that the Consultant there was better and she was much nicer but the prosthetists were useless and they were better in the first centre but you're learning as you go along, didn't know that at the time...

Complaining

Parents were generally not keen to complain - complaining was usually not viewed as the best approach and parents balanced up the benefits against the drawbacks and often controlled their anger or frustrations and modified their responses in recognition of the gate-keeping and powerful role of the professionals who held the key to what was needed by their child.

Gina commented: ...you don't want to complain, because at the end of the day, these people are helping your child and, you know it's free. it's not free, but it is, really. It's not like I'm having to pay for things and I really sort of appreciate the Health Service now...

Different strategies were used by parents, for example, knowledge gathering from observation or asking questions and hyper-vigilance. Whilst some parents would be confrontational in their approach with staff when they felt it was necessary (perhaps they saw the staff as able to alter things) others chose a

more strategic approach providing staff with ammunition to affect changes (where they felt staff themselves were not in a powerful position). Lack of opportunity to feedback on their experiences was seen as problematic as some parents did not really want to complain but they had some negative experiences that they wanted to avoid again, for themselves and for other people.

Norma acknowledged that she was an 'old hand' and felt that there had been a deterioration in the quality of the service during the time she had attended with her daughter (over a year) and especially since departments had amalgamated. She felt able to confront staff when she needed to since she said she had always been 'vocal'.

Norma: you can see the difference; they're just headless chickens.. And you want to see somebody and there's nobody there to help you at times.

I. Right..

Norma: Erm, because I'm a regular, you know what's going on and you know what to do but the care has changed.

She explained that, in the past, the nurses had more time to play with the children and this was no longer the case.

Norma: ...it was just so much nicer. And they had time to spend with the children, whereas now it's just you're in; you're in a process..I can't even say in and out because treatments that...Lana's on a treatment that would last an hour. She'll get an injection and then she'll be on another hour. But you can't guarantee you'll be out in two hours. you could be there for the day, because it's so slow: the process is so slow. There's nobody there to come and do the next bit. [Norma explained that she

would often have to go and look for staff if the machine beeped but staff were not always free to respond.]

Norma: Er, and I have had a few altercations with a few members of staff there, 'cos I say what I feel, basically...I've complained. [Norma explained that she would arrive early in the day for her daughter's one hour infusion and would need to leave by early afternoon to pick her other child up from school].

Norma: In the end, you have to say, "Look. I have to walk out at two o'clock"...

Norma: It sort of builds up. You can see it sort of building up and then you have to say something. I mean I've said to our specialists before: "you know, it's ridiculous how long it's taken you..."

Norma : I've had chats with the manager on the ward before. Erm, because she was horrified by how long it took you know...I can't remember exact instances of what I've had chats with her about. Erm, and I've spoken to sort of our team that look after us...and they sort of deal with things.

Norma's attitude to complaining when she felt it was warranted was different to strategies used by other parents.

Gina: ...and when the thing happened with the DMSA [the test had to be abandoned as the child could not cooperate and the staff had been unaware of his special needs until he had entered the x-ray room] , we were talking about it and I said "it's not that you really want to complain, because I think 'complain' is probably too strong a word." I think when

you're out in a restaurant or something like, that's a total different sort of ...you can't put them in the same category. But we said maybe there should be somewhere where you can say: this is my observations, or this is my experience. Erm just to help other people I think, in future...

There was a general reluctance to complain about care. However, if all else failed to make a difference then parents would consider complaining. Their role as protector and advocate made them feel that for their child's sake they sometimes needed to say something even though it may make no difference, they needed to voice concern and object even if they felt powerless and their complaints would be likely to make no difference.

Helen: just occasionally you come across someone who is clearly not very paediatric [Justin had broken his finger and needed some treatment]...he was creating because he often did create and the nurse was so bad tempered with him and said " well, I am just going to send you home and I won't be able to do anything for you and I will report you to your GP ..."

and that is the only time ever that I complained [formally] and I did write a letter on that occasion and I got a letter back from the Chief Executive saying thank you for your letter about your son Andrew [laughs] so I thought, well, there's no mileage in that, forget that..

Brian: Yeah. I am not a complaining type, it's just, you know..Maybe you should complain more. I was just glad he was back. That was the overriding factor really. And I was shattered so...you know. Maybe I

should have, but then you know, it's counterbalanced by the care you got afterwards as well, you know?

I.: yeah.

Brian: Yeah. So you know, can't complain about that at all. And aftercare, when I went up in the February, it was good, the female doctor we saw and everything.

I: Ah ha

Brian: It was good. It's just that initial bit, you know? Erm, yeah, but I think through the night and through the day, it was good, I think. Even though the ward wasn't great, thinking back, it was like: 'gosh', it wasn't a nice ward.

Parents behaved in ways that they felt would obtain best results and they balanced up the pros and cons by considering the reasons for complaining and for not complaining. Parents identified different reasons for not complaining which included: not wanting to annoy staff; not wanting to be seen as complainers; believing it was not the staff's fault but the system; that the staff were powerless in the situation too or parents felt gratitude for other aspects of the care. The following extracts from different parents and interviews exemplify these viewpoints.

Angela: 'cos, you don't want to get their backs up...

...

Angela: ...'cos you're sympathetic , 'cos they're busy. you know and they're waiting on the doctor and they can't necessarily hurry things up...

Graham: I mean, I don't think I ever did register a sort of formal complaint...erm, you know I'd like to say "Oh I didn't want to get that woman [receptionist] into trouble" you know, but that wouldn't be true; I'd have been very happy for her to get into trouble.

I.: Yeah

Graham: Erm, but I think it was more just, you know, often complaining it takes time, doesn't it. And you know, sometimes you feel like it's not going to get anywhere anyway or nothing's going to happen, so why bother? ...things move on and life's busy and you haven't got spare ..the free time to complain in the way that you probably should do, or might do.

Norma: ...but as usual, they're run off their feet.

I.: I see.

Norma: It's not their fault really. Not enough nurses. But that's just the general case of the whole system I think now. There's just not enough nurses to cover what's going on.

Gina: ...Because you don't want to look like you're causing trouble; you don't want to be seen as "oh, God, it's that woman again".

However, parents were more likely to complain about something if they felt that it might happen again to themselves or others; it was within the staff's control; no-one seemed to be listening; their child was in danger; it was not best for their child's health or well-being; it was not fair or purely that it needed to be said, even if it had no outcome, for the sake of their child, they had to say it on

their behalf. It was clear even when complaining formally some parents were concerned about how they may appear as a complainant.

Angela: ...and I thought if I have to go through all this again to try and persuade him to go back, knowing that I don't think it's a very good service, you know...

Angela: ...I was very aware that I must be polite and very reasonable and calm, because I didn't want to come over as a bolshie irate mother [laughs] calm sensible person.

(This mother had commented on the unsuitably of the environment to the receptionist at the time of her son's first treatment appointment but when the comments seemed to go unnoticed she asked for a feedback/comments card. The lack of response to her extensive written comments prompted her to make a formal complaint. The experience described occurred within dental services not within the children's hospital but were detailed during discussion about attitudes to complaining).

Parents who had formally made a complaint in writing or less formally to a senior member of staff had done so because they believed they had to do it. The decision to do this seems again to be grounded in their need to protect their child or to get the best for their child - to change something for the future care, to stand up for their child where they felt that they had not been treated fairly or to ensure that someone in authority within the hospital should know about the matter. In this study formal complaints were not viewed by parents as the best strategy for them to employ most of the time as this would mean they may be viewed as complainers. The unspoken power and control of health

professionals was evident, if not always expressed directly, as parents acknowledged their position within hospital and how they would act differently in other environments but the fact that it was a hospital and their child - not only their child but potentially their child's life or at least their well-being that was at stake.

Parents did recount situations where they had felt annoyed or upset during their hospital experiences but they did not always show the full extent of their feelings to the staff. Some parents shared their annoyance and frustrations with friends and family members or other parents, at the time or later. However, their expression of these feelings to staff were more controlled and the sense of the dilemma for them in actually showing or voicing their feelings is palpable in the transcripts.

In this excerpt Graham explains how angry and frustrated he felt when he realised that after a long wait in the assessment unit he discovered that the receptionist had forgotten to record their arrival. His son felt ill, was in pain and was lying across chairs in the waiting area within sight of reception.

Graham: ... at the time I was furious actually yeah. I mean I wouldn't have... You know, I didn't shout at the woman or anything like that...she was very apologetic, you know, rightly so, but, I didn't try and hide my frustration, but you know, neither did I become abusive about it, you know.

I: Yeah.

Graham: So yeah, I was angry and I kind of sat down, phoned Angela [his wife], ranting “stupid woman”, you know, so, yeah I was very angry. Yeah. And I think I suppose probably all the more so, ‘cos it was, well, because it was a child; because it was our child and because he was clearly in a lot of discomfort and pain, you know, and so yeah, it was... probably frustration’s putting it mildly. Yeah, I was angry yeah.

In considering the situation, he did recall speaking to his wife about raising their concerns about this with staff. The tone of the proposed feedback, however, sounded fairly gentle in comparison to earlier descriptions of the anger, frustration and concern felt at the time. This excerpt reflects other parents' narratives and is a clear example of change in tone compared to the earlier recollections of emotions evoked by the experience.

Graham: ...I think I said something like “look, you know, make sure that...” not that this woman gets fired, but “make sure that we register our displeasure about this in some appropriate way”. [Graham's wife came in to take over from him in the assessment unit]. ...I can't remember quite what we did and I certainly thought about it... you know? I certainly didn't want to get anyone in trouble in a sense, but at the same time, you know, just felt...

Whilst parents spoke of thinking about formally complaining most had not done so having weighed up the advantages and disadvantages of doing this. They were generally more tolerant of issues where they could see staff were busy; where they felt it was not the individual's fault or where they did not see staff as being able to do anything about the problem. If parents felt that no harm was

actually done, in the end, then they appeared to be more tolerant of situations which had previously caused them to become annoyed or frustrated. There was a tolerance of events and evidence of moderation of their feelings and perspective over time from events.

Graham...so it was quite a while ago. So erm, you know, even now I struggle a bit to remember the details. So I think erm, you know, I've kind of moved on as it were; it's not something that eats away at me or anything like that and there was no... in one sense, there was no harm done.

Parents were understanding of pressures on staff and made allowances for this when they considered their responses to situations that made them feel unhappy or annoyed.

Gina:... everybody's so caught up in what they're doing that nobody's got the time to think. Everything's sort of automatic; you're just part of the process, which again, I can totally 'get' given the amount of people that are involved and how stressful it must be for people working there, but I think sometimes, the fact that you're a person is totally forgotten...sometimes it would be nice to just have somebody to sort of say to: that went really well today thanks very much. Or this was good, or this wasn't so good...you know have you thought about how you managed this process, or whatever. Erm so I don't think it's complaining but it's more just trying to make the situation better.

The lack of opportunity for parents to feedback on their experiences was noted by parents and whilst this means that staff may be less likely to receive poor ratings or complaints about their service it also means they do not find out which elements of the care parents appreciated and valued. Opportunities to learn from positive feedback as well as negative feedback was missing in this setting.

Judging the quality

In determining their responses parents needed to make judgements, not only about potential dangers but also about the staff and services that were being provided. These initial or 'at the time' judgements were often almost unconscious evaluations of situations that triggered certain emotions and prompted an automatic or immediate reaction. Later on, parents looked back on events and evaluated the quality of the care provided much more positively than their "at the time" assessment. This difference in evaluations 'at the time' and later reflected their moderated evaluation which took into account their own heightened emotions at the time as well as their past experiences and subsequent knowledge - their 'on balance assessment'.

Perhaps, more importantly, these evaluations were influenced by the extent to which parents felt the staff or the service were effective allies in protecting their child from danger or in advocating for their child's needs. There were also some aspects of care that were critical satisfiers in parents' determination of quality whereby - if no harm was done and the essential treatment or access to experts was not hampered - then other, less satisfactory, elements were

tolerated. This did not necessarily mean that their opinion of these experiences were altered over time but, when they reflected on these events alongside the whole experience and gave an “on balance” opinion, this was usually a much more positive appraisal. These short excerpts demonstrate this effect as parents look back with a different lens than they did at the time.

Graham: But erm, no, I think, whatever it is now, nine months down the line or whatever, I kind of feel it's in terms of the big picture, it was one little mistake and, it would be wrong to let it cloud my whole judgement of the system and of the service, you know. And as I say, I think the good experiences that we've had far outweigh that particular incident.

Another example was when Gina talked about feeling they had been lucky to see so many specialists at the beginning with Thomas although 'at the time' this felt overwhelming for them. It was not until much later that she realised that some parents had suffered great difficulties in accessing specialists because their child's problems were not fully recognised by health professionals.

In judging the quality of care parents were influenced by the extent to which the staff and services helped or hindered them in achieving their goal of protecting their child from danger and whether they believed that professionals were advocating for their child. Clues that indicated that staff or services were of good quality was acknowledgement of the family's outside world and indications that their individual child and family were seen as important. Clues that indicated that professionals were acting as allies to parents in their role as protector and advocate or took on these roles themselves were highly valued. However, where this did not happen parents felt alone and viewed care as poor

quality. Parents took it for granted that they had to live in their outside world but also move between the 'two worlds'. Parents did not expect staff to acknowledge the challenges this posed for them but where staff empathised with them, this was valued and recognised as a sign of caring and personalisation of care. Staff who helped parents to understand potential dangers in the hospital world and the best ways to move forward, were appreciated as were staff who acted as 'interpreters'.

Conclusion

The findings presented in this chapter showed that parents made judgements of the care provided based on their interpretation of the clues they found during their experiences (see Figure 6). Their interpretations were affected by the personal lens through which they viewed the clues and this lens was created from their own personal life perspective. However, this lens altered as they moved along the continuum from being a new parent to a regular or old hand, gaining experience and knowledge of the hospital world on this journey (see Figure 6).

Their experience and acquired knowledge helped them to adapt through controlling elements of their experiences which they could anticipate and manage. Parents used their insider knowledge or information they had since gathered ('now know') as a regular, to respond in ways that they believed were the best approach. The best approach was one that they deemed would gain what their child needed to keep them safe and would result in the best outcomes for them ('on guard and on behalf') (see Figure 6).

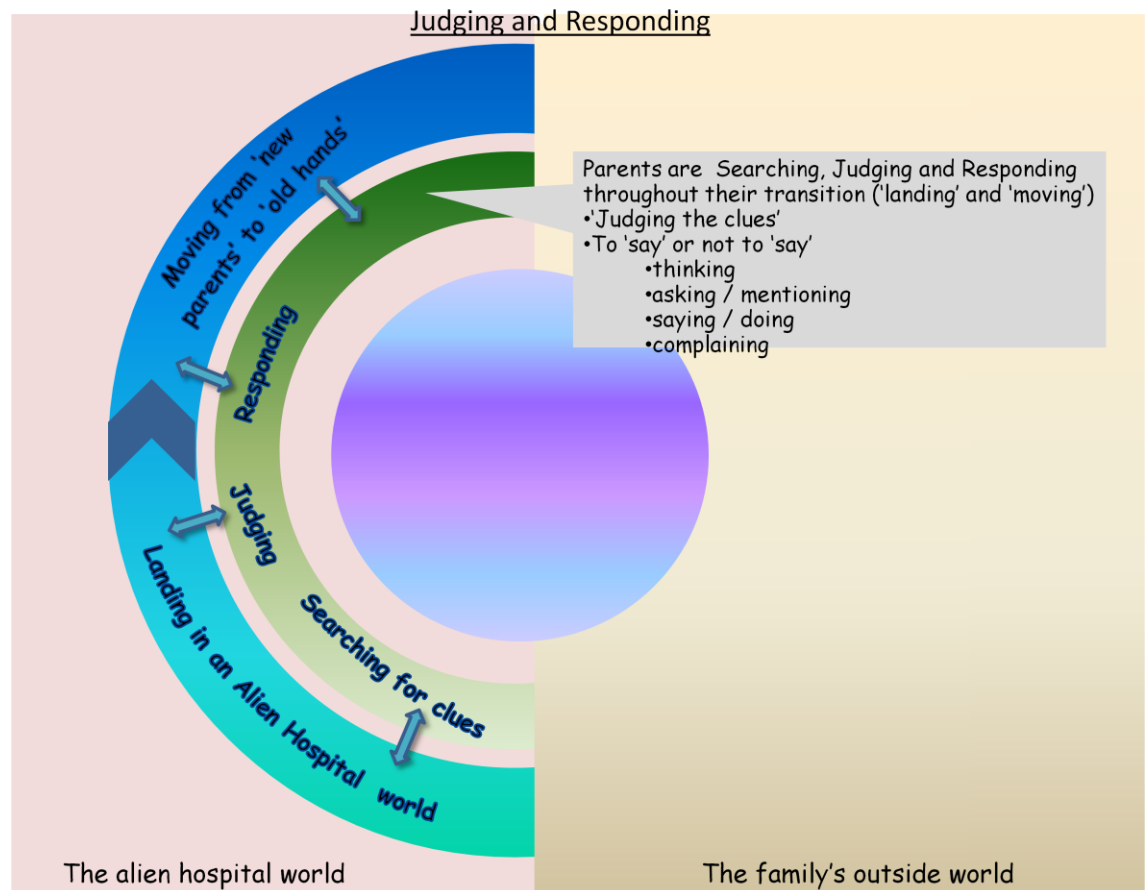
When parents faced an issue of concern to them they decided whether to say or not to say something about it to the health care professionals. Parental responses included thinking, asking, mentioning, saying, doing something or complaining (see Figure 6). Complaining as a possible parental response brought difficult dilemmas for parents as they struggled to determine the benefits and drawbacks of this approach for their child. Decisions by parents about when a complaint would bring about the best outcome for their child was influenced by parents' personal lens, their belief that the staff could bring about an improvement or that they needed to complain for their child's sake. Complaining was often seen as a last resort by parents.

The power and control of the professionals and dependence of parents on them for their child's care, safety and well-being put parents in an unenviable position. These dilemmas were stressful for parents as they aimed to protect their child and do the best for them. Judgements of the quality of care 'at the time' reflected almost unconscious evaluations of situations that triggered emotional and immediate reactions. Later, parents looked back and judged care more positively - their 'on balance' judgement. The differences between the 'at the time' and 'on balance' judgements reflected how parents moderated their earlier evaluation of care by taking into account their own heightened emotions at the time as well as their past experience and subsequent knowledge (see Figure 6).

In judging the quality of care provided parents were influenced by the extent to which the staff and the services helped or hindered them in achieving their goal to protect their child from danger and whether they believed that they too were advocating for their child- to gain the best for them. In essence, whether the

parents felt they were on their own or had allies in their role as protector and advocate for their child.

Figure 6. Judging and responding



Chapter 8 Discussion and Conclusions

Introduction

In this final chapter, the study's purpose is briefly re-visited, followed by a presentation of the grounded theory. The unique contributions this study provides to the existing knowledge base are then explored through analysis of the theory's fit with existing knowledge. A critical evaluation of this grounded theory study is presented and the implications for children's health care policy, practice, education and future research are discussed. Finally, the thesis concludes with the key messages emerging from this study.

The following sub-headings provide a framework for the discussions:

- ***Grounded theory of parenting in an alien hospital world - on guard and on behalf***
 - *Parenting - on guard and on behalf: with or without allies*
 - *Landing, moving and personal lens*
 - *Searching and judging*
 - *Responding*
 - *Judging quality*
- ***Grounded theory in an alien hospital world: contribution to knowledge***
 - *Landing and moving*
 - *Judging and responding*
 - *Are parents like customers when judging quality?*
 - *Parental signalling- queries and concerns*
 - *Professionals: power and control*
 - *Parents: protectors and advocates*
- ***Strengths and limitations***
- ***Implications for policy, practice and education***
- ***Implications for future research.***
- ***Final conclusions***

Purpose of study re-visited

The purpose of this study was to explore parental perspectives of the quality of their child's hospital care and increase understanding of the factors influencing

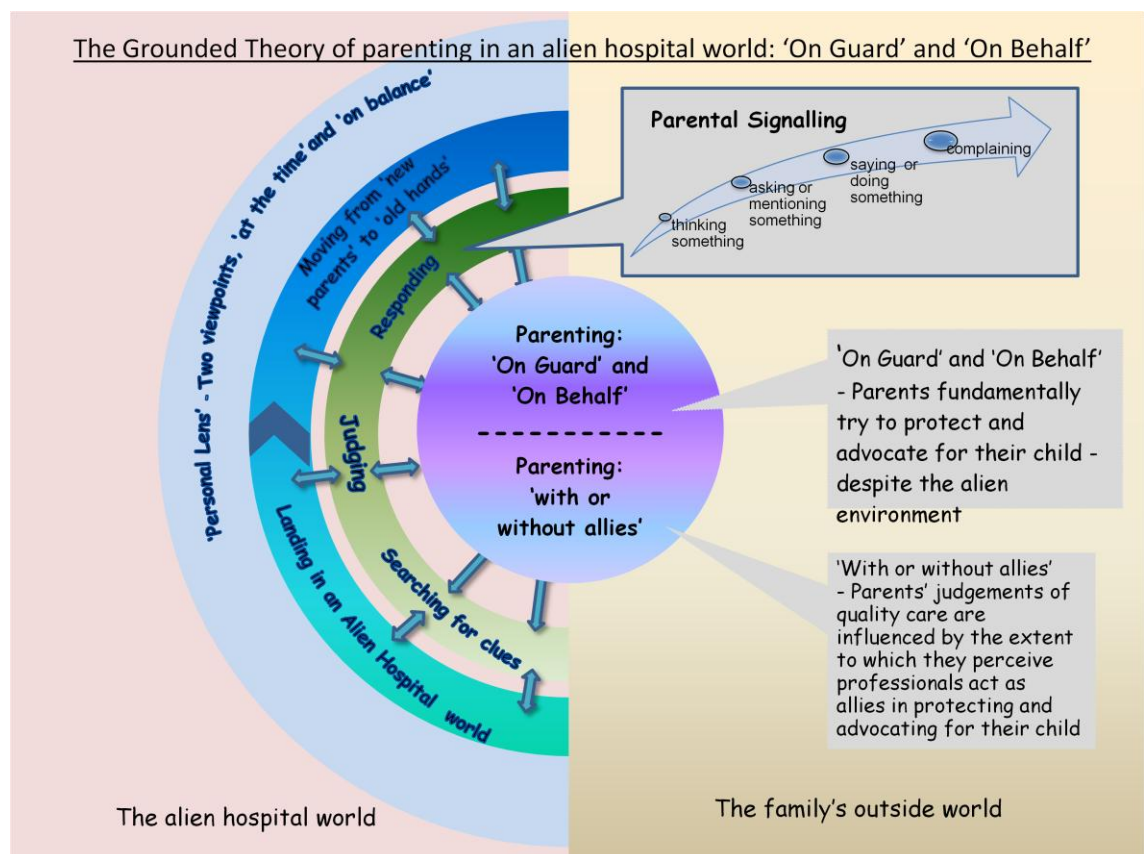
these quality judgements. The research also set out to explore the notion that parents' perceptions of the quality of care may change over time in the way that has been reported in adult patient studies.

The substantive grounded theory constructed within this thesis presents some new perspectives on the complexities of the psychosocial processes that underlie parents' interactions with hospital staff and their expressed judgements of the quality of their child's hospital care. In following grounded theory, exploration of phenomena involves identification of the basic social processes occurring within the situation under study. Glaser and Strauss (1967) emphasised the need to discover the single social process that incorporated the actions and explanations of the situation. However, Charmaz (2006) has since proposed that it is not always possible to uncover one basic social process as often there are several basic processes occurring within the studied setting or experience. In this study, several basic social processes were highlighted that captured the parents' experiences of their child's hospitalisation and the parents' quality evaluations of the care within those experiences. Parents moved from being 'new parents' to being 'old hands' through the experiences and knowledge gained through 'searching for clues' and 'interpreting the clues' and throughout this transition parents were 'judging' and 'responding' to a range of experiences. Further explanations of these concepts and the way that they were subsequently integrated within this grounded theory are provided in the next section.

Grounded theory of parenting in an alien hospital world - 'on guard' and 'on behalf'

The substantive grounded theory constructed from the data is summarised here, accompanied by a diagrammatic representation of the theory's central features (Figure 7). Figure 7 combines the major concepts presented within Figures 4,5 and 6 to provide a full visual portrayal of the complexity of the psychosocial processes occurring within parental quality evaluations of care.

Figure 7. Grounded theory of parenting in an alien hospital world - 'on guard' and 'on behalf' and 'on behalf'



The theory recognises the existence of two 'worlds' for families, an alien hospital world and a familiar outside world and this sets the broad context for the theory (these different worlds are illustrated in Figure 7 by the central dividing line and use of two background colours). Furthermore, the central concept of parents protecting and advocating for their children (on guard and on behalf) is identified as a core aspect of parenting that occurs in both worlds (Figure 7).

Parenting - on guard and on behalf: with or without allies

The grounded theory of parenting in an alien hospital world is built around two central concepts that emerged from data analysis. Firstly, the notion that most parents are fundamentally driven to protect (on guard) and advocate (on behalf) for their children and this is an essential part of 'parenting'. The shock and anxiety of landing in the hospital world, coupled with the frightening, unfamiliar and emotional nature of the situation is challenging for parents, as they attempt to continue in their parenting roles as the protector and advocate for their child.

Secondly, the concept that parental quality judgements of their child's hospital care is influenced by the extent to which parents' perceive health professionals act as their 'allies', helping or hindering their parental efforts (with or without allies) to continue protecting and advocating for their child.

Landing, Moving and Personal Lens

The grounded theory identifies the parental experiences of their child's hospitalisation as one of landing in an alien hospital world and moving from

being new parents to old hands. Parents enter and view the hospital world through their own personal lens - a lens developed through their previous life experiences, knowledge and attitudes. However, during the transitional journey to become 'old hands', alterations to their lens may occur as they make sense of the new experiences for themselves or with the help of health professionals. Where the hospital experience is short lived (less than 48 hours) the transition begins but is then cut short as they are discharged home, leaving parents greatly relieved as they 'escape' back to their familiar outside world. However, they also feel guilt and empathy for those families that they have left behind. Regardless of whether parents' hospital experiences are short or long term, three main psycho-social processes were identified: searching for clues, judging and responding. These processes take place from the beginning of the experience, where parents are new parents and continue throughout the transitional journey as they become old hands.

Searching and Judging

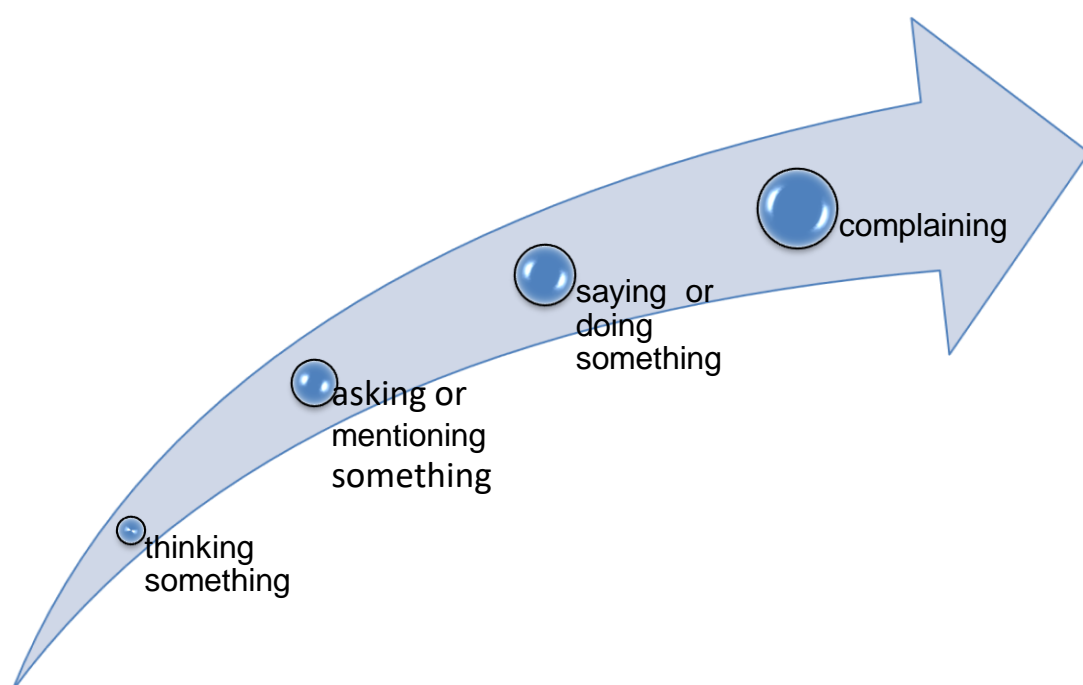
Parents are highly vigilant, searching for clues to assist their understanding of their situation and they continually make quality judgements of care based on their interpretation of these clues. Interpretations are dependent on their own personal lens which alters as they gain more experience and knowledge of the hospital world. Understanding of this alien world ('we now know') occurs through parents finding out information for themselves or professionals (allies) acting as interpreters for them. Parents use their new knowledge to adapt to or control elements of their hospital experiences wherever they are able to anticipate and manage situations. Parents simultaneously judge and respond

to 'clues' from the perspective of their central need to continue in their parenting role and more specifically to protect and advocate for their child.

Responding

Parents' responses to health professionals are varied but are driven by their own beliefs about what actions may be most beneficial for their child (on guard and on behalf). When parents have a query or concern about their child's condition or care they often face a dilemma about whether 'to say or not to say' something to health professionals. This grounded theory has identified that parents carefully choose the way they raise queries or concerns with staff - asking or mentioning something; eventually saying something, doing something or complaining. These different 'signals' by parents are used to try to evoke a response from professionals and are escalated through the levels when parents feel it is best to do so (Figure 8).

Figure 8. Escalating levels of Parental Signals



Parental conscious or unconscious use of signals from invisible, implicit signals to more visible, explicit signals reflect parental perceptions of the power and control of professionals, their dependency on the staff and their desire, generally, not to 'rock the boat' or 'get their backs up'. A visual representation of parental signalling when they have a query or concern is presented (Figure 8). Parents' weigh up their possible responses within the context of their own beliefs regarding the powerful position of health professionals and the risks of potentially jeopardising their child's care through their own behaviours. Factors that may further moderate parents' decisions about which response is most likely to yield best outcomes for their child, relate to the desire to act within social norms and maintain cordial relations with professionals. Complaining as a parental response is seen as difficult by parents and an act of last response. It is used by parents when it is felt it will bring about the best outcome for their child and this is influenced by their own personal lens; their belief that staff can bring about an improvement or where they feel an obligation, as an advocate for their child, to complain.

Judging Quality

Parents hold two views of their child's hospitalisation - 'at the time' and 'on balance' and these views are dependent on the parents' personal lens when the evaluation occurs and the subsequent degree of parental moderation and tolerance. Whilst all parents will enter the hospital world with a different personal lens through their own life experiences, viewpoints and opinions, the impact of their hospital experiences change their perspectives as they adapt

and move along the transitional journey. Judgements of the quality of care 'at the time' reflect immediate evaluations of situations, often triggering emotional and spontaneous reactions. Later, when parents look back on hospital experiences they provide an 'on balance' judgement of care quality which is more positive. The 'on balance' judgement is a moderated and more tolerant evaluation and takes account of their own heightened emotions at the time, their past experience and subsequent knowledge. The 'on balance' view also recognises the lowest level of care provision parents deem acceptable before they complain. Factors considered by parents with regard to raising a complaint are guided by whether they feel any harm occurred; whether it was a "one off" event and whether, ultimately, the key needs of their child were met. These findings provide a new contribution to understanding of parental judgements. Parents still hold both 'at the time' and 'on balance' views of their experience, their view is not transformed or replaced as has been described in studies of adult patients. In judging the quality of care, parents are greatly influenced by the extent to which they perceive health professionals act as their allies as they try to continue parenting (on guard and on behalf) their child in the alien hospital world.

Grounded theory of parenting in an 'alien' hospital world: contribution to knowledge

Landing and Moving

The grounded theory of parenting in an alien hospital world adds to the existing evidence about the impact on parents of their child's hospitalisation. The

powerful narratives remind us just how alien everything felt to parents when they suddenly found themselves stepping from their own familiar outside world and into the alien hospital world. The notion of two worlds of existence operating for the parents was recognised within the construction of the grounded theory. The strange, frightening and often unknown nature of hospitalisation for children and their families and the disruptions caused to their normal lives are familiar concepts in children's nursing and have been previously well documented (Darbyshire, 1994; Sartain et al, 2000; Sartain et al, 2001; Smith and Callery, 2005; Coyne, 2006a; Coyne and Cowley, 2007; Carney et al, 2003; Pelander and Leino-Kilpi, 2010; Tong et al, 2010; Fletcher et al, 2011; Coyne and Kirwan, 2012; Higham and Davies, 2012; Peeler et al, 2015). In this study, professionals who acknowledged and accommodated the tensions this created for parents, were valued by them, although this was not always the parents' experience of professionals. Existing literature has suggested that nurses may not fully appreciate the impact on parents of their child's hospitalisation nor the extent of their fears and anxieties (Miceli and Clark, 2005; Avis and Reardon, 2008; Tong et al, 2010; Peeler et al, 2015). Equally nurses' familiarity with the environment and possible perception of events as fairly routine compared with parents' views may reduce nurses' responsiveness to parental anxieties. (Peeler et al, 2015).

This study adds to this literature by proposing that whilst it is important for nurses to fully appreciate the heightened level of parental anxiety, it is crucial that they clearly demonstrate this empathy to the parents. It also appears that when parents are in a state of distress or feel vulnerable they are more ready to accept open demonstrations of care and concern from people than in normal circumstances. The findings reported in this thesis extend the

knowledge base in this area by highlighting a central parental need for professionals to engage in open communications, explicitly show concern and visibly acknowledge parental anxieties. The explicit demonstration by professionals of their appreciation of the heightened emotional state of parents when their child is hospitalised facilitates the development of trusting relationships and identification of professionals as parental allies.

In this study when the hospital experience was a short lived or single event, parents described their joy and relief at being able to return to their normal and familiar world at home. However, they also recounted feelings of guilt and empathy for those families continuing to have to live within the hospital world or between the two worlds of hospital and home. These feelings seem to bear some resemblance to those described as 'survivor's syndrome', a term originally used to describe a set of emotional reactions to major traumatic events, for example, hostage situations, war, natural disasters. The term has been adopted and used to portray the emotional impact of adverse events on people in a range of other much less extreme situations, for example, in management studies where individuals have survived redundancy or organisational restructuring (Brockner et al, 1985; Baruch and Hind, 2000). The common theme within all of these situations are the way that they evoke feelings of guilt in the individual when they have 'survived' the event and their lives return to normal but also increased empathy for the other individuals who have suffered less positive outcomes. In this study parents' accounts recognised their child's hospitalisation as being an event that threatened the child and family's biography with the potential to affect their past, present and future lives. Although for some parents the experience was a single event with changes to their lives being short lived, for others this was the beginning of a continuing

alteration to their circumstances. Bury (1982) first described chronic illness as a biographical disruption when he explained how the lives of people with chronic illness was altered by their illness or injury. Such disruption to a family's biography and subsequent accommodation (Sartain et al, 2000) have also been acknowledged where a child has on-going health problems. The need for individuals and families to re-frame their lives, taking into account the changes that illness and injury has brought for them has been noted (Moffatt and Murray, 2010). The disruption of normality and alteration to the family's anticipated future was articulated very clearly in many interviews within this doctoral research and is reflected within three key categories within the grounded theory: two worlds; landing in an alien world and moving from being new parents to old hands. These findings add to existing knowledge regarding the impact of a child's hospitalisation on the child, parents and their family and act as a keen reminder for health professionals to fully appreciate the psycho-social context within which their interactions with parents take place. To improve the parents' experiences, this study demonstrates that when their child is hospitalised, professionals need to consistently and explicitly acknowledge the parents situation, in terms of the disruption and alteration to their family's normality.

Parents in this study who had a long term relationship with the hospital moved from their original position as being new to the experience to becoming 'old hands'. These parents eventually found their own ways of managing some of the difficulties or tensions of being in the hospital or living between the two worlds of hospital and home. They learned by experience how some of the hospital systems worked and developed their own ways of responding within these situations. The findings reported in this thesis highlight the ways in which

parents were hyper-vigilant as they searched for clues to help them to understand their situation so that they could protect and advocate for their child in the unfamiliar hospital territory. This knowledge extends current understanding of the way that parents behave when their child is undergoing hospital treatment, by revealing key motivators for their actions whilst also demonstrating the value parents placed, on feeling they were not alone in their efforts to make sense of the risks within the situation. These findings are consistent with previously reported vigilance of parents when in hospital with their child and the notion that parents feel the need to watch over their child's safety (Snowdon and Gottlieb, 1989; Balling and McCubbin, 2001; Dudley and Carr, 2004; Cox et al, 2013; Tong et al, 2010; Coyne, 2015; Peeler et al, 2015).

Several studies report that parents identify that trusting the professionals to deliver best care is an important element in reassuring them of their child's safety (Shields et al, 2003; Shields et al, 2004; Shields et al, 2008; Peeler et al, 2015). The findings from this research study, however, extends our understanding further by showing the way that parents were constantly searching for details of what was happening and explanations for what they were observing. They then interpreted this information on their own or with the help of professionals. When parents felt they were alone in making sense of the situations this was viewed negatively by parents who associated high quality care with times where they felt professionals were their 'allies' and acted as their interpreters.

One of the most important contributions this study makes to existing knowledge relates to the nature of the health professional-parent relationship. In this

grounded theory it is proposed that parents perceived care to be of high quality where health professionals had acted as their 'allies' in their parenting role of protecting and advocating for their child. This notion of professionals being allies to parents presents some challenge to existing thinking within children's nursing where the central tenet for many years has been the concept of professionals being partners to parents (Casey 1995; Callery and Smith, 1991). The selection of the term 'allies' rather than partners, in this grounded theory, has been specifically chosen because of the subtle differences between the meaning of these two terms. Allies, suggests a joining of forces supporting and strengthening responses to potential threats. The term partners also denotes joint involvement in an activity but suggests equity in the relationship whereas an ally is defined as being someone who co-operates with or helps someone else in a particular activity, where this help is required (Oxford Dictionaries, www.oxforddictionaries.com/definition last accessed 20.1.2016). In the case of the parents in this study, the alien nature of the hospital world presented challenges for parents beyond their usual experiences and knowledge and they wanted health professionals to act as allies to them to meet their child's needs and keep them safe.

In this study, parents' overall judgements of care quality were determined by the extent to which they perceived health professionals had acted as allies to them as they attempted to 'parent' their children. The specific influence of staff-parent relationships on parental quality evaluations is something that has not previously been given a high profile in quality assurance systems (Beal et al, 2004). Standard measures of quality have usually focussed upon structures,

processes and outcomes within hospital care without appreciation that this important element in parental evaluations has been somewhat overlooked. Coyne (2007) has previously recognised the importance of parental support by children's nurses and proposed that sufficient resources including time be allowed for this key aspect of family centred care. Furthermore, Coyne (2007) argues that care of parents by children's nurses should not only be a quality standard to be attained but also to be valued and acknowledged by nursing management. The findings presented in this thesis suggest that further efforts to improve parental perceptions of the nurse-parent relationship, specifically related to their own key drivers as protectors and advocates for their child, would positively impact on parents' quality evaluations of care.

In proposing a shift in thinking towards health professionals acting as 'allies' to parents of hospitalised children rather than 'partners' with parents, the fit with family centred care needs consideration as partnership in care is often viewed as a key feature of this approach to care (Coyne 1996; Shields et al 2012). The family is central within family centred care recognising its important role in the child's health and well-being: operating as both a model of care delivery and a care philosophy, family centred care has been embraced in children's healthcare provision globally (Shields et al, 2012). This study's findings provide additional support for family centred care as the impact of the child's hospitalisation on the whole family were evidenced in the parents' accounts, in addition to the family's need for health professionals' support. The findings also demonstrated that parents valued effective relationships with health professionals although the aspects most valued by them in this study highlights some differences between existing knowledge supporting the concept of partnership with parents.

Debates surrounding family centred care have been on-going for some decades reflecting tensions between the theoretical concepts and the realities within practice. Darbyshire (1994) was one of the early researchers to suggest that whilst the ideals incorporated in this approach to care were laudable the concept was a difficult one to put into practice. More recently, Shields et al (2007; 2012a; 2012b) cognisant of continuing issues with this approach to care, undertook two Cochrane Systematic Reviews (Shields et al, 2007; 2012a; 2012b) to examine the effectiveness of family centred care as a model of care. The conclusion was that it was difficult to ascertain the effectiveness of family centred care for children and family's health outcomes due to a lack of appropriately rigorous evidence. Whilst the systematic reviews attempted to examine and measure outcomes, Carter (2008) provided a reminder that family centre care is a philosophy of care and, as such, is built upon a set of shared beliefs about what constitutes best care. It is suggested that it is perhaps our beliefs in a family centred approach to care that prevent us from abandoning the concept despite the difficulties it entails. It is proposed that it is 'reason' rather than research evidence that has made us believe that when it is working this is a 'rewarding and satisfying' way to provide care (Carter, 2008, p. 2092). However, given the complexities involved and the many factors impacting on its success it is perhaps not surprising that it does not always work well. There is an argument for continuing to pursue family centred care despite its problems, recognising that any model of care may face similar difficulties given the complex and growing demands on current services and the wide variation of needs of families. The debates have continued about family centred care, with Shields (2010; 2011) warning nurses to beware of creating 'a sacred cow' out of family centred care and questions the reality of the concept, given continuing

problems in operationalising the model, she suggests that we may need to abandon it and consider a new model.

In researching the problems associated with family centred care, Coyne et al (2011) proposed that key issues underlying provision of optimal family centred care may be due to organisational and environmental factors rather than lack of support or negative attitudes amongst nurses. It was suggested that nurses needed to be both 'vigilant and vocal' with regard to ensuring adequate staffing levels and facilities for optimal care provision for families (Coyne et al, 2011,p.2570). The findings reported in this thesis provide the parents' view as service users and demonstrate how these parents equated quality of care with professionals who worked alongside them providing support by informing, interacting, explaining and interpreting for them. Whilst Coyne et al (2011) have called for nurses to be alert and speak out if insufficient resources thwart their attempts to provide best care the service users' voice in today's NHS may actually prove more persuasive. Parents views heard within this doctoral study contribute evidence to support children's nurses' requests for appropriate staffing and organisational support for family centred care. Given the current emphasis in the NHS to listening and responding to service users' views, findings from this study could potentially be more impactful than nurses' voices in the quest to secure appropriate resourcing for family centred care.

Adult services are facing similar pressures as they struggle to cope with increasing admissions of older adults normally dependent on relatives as carers. There may be mutual benefit in recognising the value of family centred care within both child and adult services and joining forces to address

resourcing issues. Adult nurses may benefit from children's nurses' sharing with them their extensive experience of resident parents and their involvement in care. Similarly, where adult nursing services may dominate hospital agendas it could be beneficial for family centred care to be viewed as a top priority for both patient groups which may prove more effective and also encourage a cultural shift in adult care. This study contributes a new dimension within the health professional relationship in adult services as well as children's services by advocating that professionals act as allies to families.

Partnership with parents is seen as a fundamental aspect of family centred care and, recently, a concept synthesis of family centred care and partnership in care has been undertaken (Smith et al, 2015). The antecedents and attributes of these models of care were identified within this synthesis. Antecedents of these models were noted as lack of role clarity; deep-rooted existing professional practices and problematic support for operationalisation of models. The key attributes of these models were identified as developing trust; appreciating parental concerns and parents' knowledge of their own child (Smith et al, 2015). The synthesis resulted in the production of a framework of involvement for use in practice, encouraging promotion of parent-professional collaboration for families with long-term conditions. However, the findings reported in the current study, detailing parents' desire for professionals to be their allies in their parenting roles, adds an important and previously unknown element to the existing understanding of parent-professional relationships reflected in Smith et al's (2015) concept synthesis. In this study, the element of the parent-professional relationship previously overlooked was that parents

appear to perceive there to be great benefit in having health professionals as their allies, because they are seen as powerful insiders within the alien hospital world.

Judging and Responding

The findings of this study contribute to knowledge within service user feedback by recognising the covert nature of parents' quality judgements of care, making it potentially difficult to access parents' genuine feedback. Existing literature in this field mainly relates to adult patients and will be re-visited here briefly before moving on to discuss new understandings of parental views offered by this study. Challenges in collecting genuine adult patients' views of their healthcare experiences were recognised when consistently high levels of satisfaction in patient surveys were reported, compared with a broader range of responses obtained through qualitative inquiries (Williams, 1994; McIver and Meredith, 1998; Edwards, Staniszweska and Crichton 2004). Refinements to the National Patient Survey (Picker, 2002) has addressed this by asking patients about specific experiences rather than their satisfaction with services, although limitations of survey methods in this domain remain. Despite these recognised problems in gaining honest service user feedback, surveys remain a frequently used method of collecting adult patients' views. Similarly, in reviewing the literature relating to parental perspectives on the quality of children's hospital care (Chapter 2) it was evident that collection of quantitative data via surveys and questionnaires was a commonly used approach. While these studies provided detailed statistics of ratings from parents on various quality of care measures they were not designed to provide in-depth explanations of scores or

to determine any underlying factors influencing parental responses. Therefore, similar to the National Patient Survey (Picker, 2002) there are some limitations in the ability of surveys to guide future quality improvements except at a generic level. It is in-depth exploration in the field of service user experience and evaluation, both adult patients and parents' perspectives, that have been able to offer greater insight into the many hidden influences on service users' real views.

The in-depth interviews within this research study has enabled new insights to be gained of the parents' views of quality care over time. Important information that was uncovered was that parents held two views of their care experiences simultaneously. Parents separated their evaluations within their narratives into their "at the time" and "on balance" views. In a sense, they still recalled and held their "at the time" view of an event but their final judgement of care, over time, took account of their changing perspective as they transitioned from being new parents to old hands. Other influences on their final evaluation came from recognition of their own heightened emotions at the time of the experience which later enabled them to look back and see things differently. These findings are particularly important because they offer an opportunity to improve future parental experiences by recognising, exploring and addressing issues arising from parents' "at the time" views as well as their "on balance" views. In addition, the findings highlight a subtle difference between parents and adult patients with regard to transformation of views over time. Existing literature in this area relating to adult patients reported transformation of their opinions of care, over time, from negative to positive (Williams et al, 1998; Edwards et al, 2004). Complex psychological and social factors were thought to account for

these changes, including patients wishing to make allowances; not wanting to make negative evaluations and their consideration of duty and culpability issues. It has been suggested that patients wanted to justify redirecting culpability for poor services away from staff who provided their care so suggested various extenuating circumstances to blame for problems, enabling them to then positively rate services.

Edwards et al (2004) further investigated the psycho-social pressures at play during apparent transformations of opinion and concluded that a complex process of 'making allowances to dissipate blame' (Edwards et al, 2004, p.176) occurred. It was considered that this was possibly a culturally British response or reflected the way people generally deal with difficult situations in their lives by rationalising away problems to maintain a positive outlook. Furthermore, it was proposed that when patients had a negative encounter and may consider complaining, three pressures combined to drive opinion transformation - the power of the system and staff; reciprocal dependence of patients and perceived limited relevance of any redress. The final "transformed" opinion it seems will not necessarily be a valid representation of patients' real experiences. So, whilst such final evaluations may be overly positive and therefore good for hospital league tables and key performance indicators it will not necessarily be a true picture of the care provided and therefore cannot properly inform real improvements to services.

In contrast the findings of this doctoral study did not find evidence of parents offering mitigation for poor hospital experiences to avert culpability away from those who had cared for their child. Although parents did see some problems

as being due to the 'system' or beyond the staff's control, general re-direction of blame away from frontline staff was not evident. A further driver in transformation of adult patient opinion was reported as their desire to maintain a positive outlook which helped preserve their own well-being. This was not evident as a concern for parents who acted to protect and advocate for their child's well-being putting their child's best interests before their own.

The findings in this study suggested that where parents had expressed strong negative feelings of events 'at the time' they balanced these up against certain benchmarks. In making their later 'on balance' judgements they took into consideration whether, in the end, any harm was done, critical needs of the child were met (for access to the expertise; the medication; the surgery) as well as considering whether this was an isolated experience compared to more positive previous experiences. These benchmarks seemed to provide the lowest acceptable level for parents in terms of their tolerance of less than optimal care and perhaps reassured parents about their own chosen response at the time.

Are parents like customers when judging quality?

Emergent findings in this study showed that where parents had low expectations of services and their experiences matched their expectations they tended to accept the service standard. As previously discussed, parents in this study had a range of different expectations of hospital care depending on their own personal life perspective. However, for parents who moved from being new parents to old hands there was evidence that when they had low

expectations confirmed they tended to tolerate and adapt. Examples of this was parental attitudes to hospital waiting, I had anticipated that this might be a major complaint from parents and found it puzzling when this was not mentioned in any initial interviews. Once directly questioned, in subsequent interviews, parents poured out stories of their many hours of waiting in different situations. One family referred to "hospital time" and talked of how they had quickly learned to arrange everything in their lives to fit in with the hospital or this added to their stress. They adapted and accepted that the system was too large for them to change and with few alternative services available to go they opted to control elements that made it easier for them, for example, never assuming a one hour appointment would take one hour and never assuming they could plan to fit anything else in their day if they were attending hospital.

These findings generally fit with the early models of retail customer satisfaction discussed earlier - confirmation model (Oliver, 1989) and disconfirmation model (Helson, 1964). Tolerance and adaptation to poor services is seen as more likely when service options are limited or where consumer power limited (Helson, 1964). However, there were differences between parents within hospitals and retail consumers, in relation to these models (Oliver, 1989 and Helson, 1964), as although willing to tolerate and adapt to many aspects of experiences parents remained vigilant for any clues that raised a worry for their child's safety or well-being. If, on their journey, they had such a concern they then had to consider whether to say or not say something about it to professionals or to complain, for their child's sake.

In this study parents used their interpretations of the clues they noticed to judge care quality. A major influence in their final judgements was whether they felt professionals had been allies to them or they had felt alone in their experiences. In the consumer literature Dale (2003) highlights the service encounter as a "moment of truth" (Carlzon 1987; Dale, 2003; Normann, 1984) and proposes that it is each moment of truth that influences customer's overall opinion of a service. This is consistent with this study's findings as with each interaction parents' interpretations added to their overall judgement and for them, 'moments of truth' were evidence within their interactions that professionals were assisting and not hindering them in keeping their child safe.

Parental Signalling - queries and concerns

Findings from this study have a unique contribution to make to the continuing debate about the perceived powerful and controlling position of health professionals. Parental responses to the situations they found themselves in was varied and driven by their own beliefs about what actions may be most beneficial for their child. When parents carefully chose a way of raising queries or concerns with staff this was described in terms of asking/mentioning something or eventually saying something, doing something or complaining. These differing levels of signalling by parents were used to try to gain a response from professionals and were escalated through the levels when parents felt it was best to do so. Parental conscious or unconscious use of signals from invisible, implicit signals to more visible, explicit signals reflected their perceptions of the power and control of professionals, their dependency on staff, as well as their desire generally not to 'rock the boat' or 'get their backs

up'. A visual representation of parental signalling when they have a query or concern was presented earlier in this chapter (Figure 8). The parents' consideration of their best response gives a sense that they recognised professionals' powerful position in situations and they had to weigh up their responses against potentially jeopardising their child's care through their own behaviour. The key factors in these decisions was the parents' views about which parental response was most likely to yield the best outcomes for their child. Desire to act within social norms and maintain cordial relations with professionals tempered parental responses but when parents felt it was necessary they would raise the level of their signalling. These findings are particularly significant for clinical practice as greater awareness, sensitivity and responsiveness by professionals to parents' signalling could help to reduce parental stress, misunderstandings and misinterpretations. In addition, this may positively impact on parental perceptions of the extent to which professionals have acted as their allies thus improving their judgements of the quality of care provision. Professionals should be aware that just because parents are not complaining or explicitly expressing their queries and concerns this does not mean that they do not have any. The covert nature and private views of parents as they considered their best responses demonstrate complexities in the psycho-social interactions within hospitals.

Professionals - power and control

Emergent findings of this grounded theory study of parental perspectives of quality in hospital care recognises that professionals underlying power within the hospital system impacts on parents' quality appraisals and responses.

Findings demonstrated that parents mainly preferred to avoid complaining about care wherever possible and for some, this was due to gratitude for previous more positive experiences and outcomes they had experienced from the health service, loyalty and appreciation of staff and the NHS. Parents faced a dilemma when thinking about complaining as they were dependent on staff and services to keep their child safe and therefore did not want to cause difficulties in relationships with the very people looking after their child. However, they also had a sense of duty and responsibility to keep their child safe and act on their behalf to protect their best interests and they needed to weigh up each situation and event, with this in mind. At times the parents found this a difficult path to tread and their need to monitor and act where necessary for their child's sake added to their anxieties.

Despite a multitude of strategies and initiatives in the NHS over many years aimed at empowering service users (DOH, 1991; DOH 1997, DOH 2000a, 2001a, Health and Social Care Act, 2001; Picker, 2002) it appears that the balance of power remains tilted towards professionals. Whilst improvements have been made and strategies adopted from business and retail to encourage patient feedback to inform service quality improvements and improve standards of care, there are some fundamental issues of professional power that continue to almost invisibly yield their control on service users.

Parents within this study were found to be generally reluctant to complain about care although they would consider this as an appropriate response where it was considered best for their child. Parents' fundamental drive to continue to protect and advocate for their child, even when in a hospital situation, dominated their

deliberations when facing a query or concern and ultimately these drives determined their decisions. Awareness of their need for health professionals' care and their perception that they needed to maintain good relationships with them, for their child's sake, marks this situation out as different from any customer/ service provider relationships.

Factors that enable or prevent consumer complaints in the retail/business world include individual's knowledge, skills, time, understanding of organisation's processes, confidence about complaining and accessibility of key staff, (East et al, 2008). Despite fundamental differences between parents and customers some of these factors may be applicable, for example, parents may not have clinical knowledge to recognise poor practice and therefore do not complain or they may not know how to formally complain or have the confidence to do so. It has also been recognised in retail/business that vulnerable consumers and those who feel powerless are generally thought to be less likely to complain (Warland et al, 1975; Andreasen and Manning, 1990). Previous discussions of power and control operating under the surface of the NHS may equally control parental complaint behaviours. Findings reported in this study further emphasise that parents in the hospital context can feel particularly vulnerable because of their heightened emotions due to their child's illness or injury, uncertainties in their situation and their dependence on professionals and services. Another factor recognised within consumer complaint behaviour is the relationship between ease and accessibility to complain and the number of complaints received by an organisation when consumers have a problem with a service (East et al, 2008). This has been recognised within the NHS and efforts have been made over several years now to enable service users to

feedback or if necessary complain and the systems are more prominently advertised than previously was the case in the NHS (NHS England, 2016). In business it is the areas of customer complaint or dissatisfaction with services that are seen as most valuable feedback for service improvement. It appears that if methods utilised to collect patient feedback repeatedly prevents health services from really hearing where problem areas exist, then there is a missed opportunity to make substantial quality changes. The uncovering of real problems by dissatisfied customers in service industries enables businesses to gain competitive edge on rivals as they refine their services accordingly. Great investment in terms of both time and money to identify real issues for improvement is, therefore, viewed as highly profitable. It seems that such openness to hear about dissatisfaction with services has been embraced by many successful organisations some time ago.

Parents - protectors and advocates

Parents are recognised in law as having responsibilities to care for their children and protect them from harm (Children Act, 2004; UN General Assembly, 1989). This role seems to be so taken for granted that the literature on protection of children focuses almost exclusively on protecting children from their parents in circumstances where their parents are not providing safe care for them (DfES, 2013). In considering parents' role in their child's protection, Hogghugh (1997) provides a useful model which identifies parents need to provide care, control and development for their child. Specifically, parenting requires parents to meet their child's physical, emotional and social needs whilst protecting them from avoidable illness, harm, accident or abuse. The control aspect of this model

relates to setting safe parameters; the development aspect to optimising the child's potential. The relevance of this model, in relation to this study's findings, are the identification of resources required to be effective parents. Parents need knowledge of how best to meet care and development needs of their child as well as being able to recognise sources of danger for their child. This grounded theory of parenting in an alien hospital world fits well with Hoghhugh's parenting model (1997) and reflects descriptions of the parental struggles as they continued to enact their parenting role of protecting and advocating for their child. Having landed in the unfamiliar territory of the hospital, many parents no longer had relevant knowledge of how best to meet their child's needs or to recognise sources of danger and this added to their anxieties and dependence on professionals. Parents searched for information to help in their quest to continue their parenting role. In their journey from being 'new parents' to 'old hands' they learned to interpret this new world 'with or without help from allies' to interpret and support them. The core category of parents protecting and advocating for their child is consistent with and centred around these fundamental elements of effective parenting.

The emergent theory identified parental advocacy as a core category in this grounded theory. Study findings demonstrated parental need to continue to act on behalf of their child's best interests although this was difficult for parents. Parents lack of knowledge and experience about their child's best interests in this setting meant they again needed to search to understand the situation in order to fulfil their role and support their child. Ellis (1995) acknowledged that sometimes nurses as well as parents needed to advocate on behalf of the child where support was needed to be assertive in articulating the best interests of the child. This notion of both parents and nurses joining forces to advocate for

the child is reflected in the findings from this study. Where parents felt that professionals had acted as their allies in advocating for their child this was highly valued and acknowledged as important to them.

Lowson et al (2013) explored adult carer relationships and their meanings when the care recipient was admitted to hospital. In this qualitative study older adults ($n=13$) with chronic illness and their family carers ($n=12$.) Researchers found that carers were seen as "conductors" when the person they were caring for was at home, however, once admitted to hospital their role altered to 'second fiddle' with a reduced input in any decision-making. This is an interesting situation for comparison to parents' role within hospital settings. Carers identified individual needs, provided care and advocated for the person. Similarities to parental roles are quite striking and the history of parental participation in care in children's nursing may offer some insights for nurses working with elderly patients and their family carers as this aspect of elderly care grows. The study had several examples of relatives stepping in to point out an issue to staff, for example, with medications. However, researchers note that such challenges may require both assertiveness and confidence.

Carers may be particularly concerned to handle such situations in a balanced and sensitive way without confrontation to avoid any potential negative consequences for the patient. (Lowson et al, 2013, p. 1203)

This excerpt sums up the position family carers may find themselves in when advocating for relatives and mirrors this study's findings as parents carefully navigated the path to ensure the best for their child. The high value placed on health professionals being allies to the parents perhaps also relates to their

recognition of the powerful position of the professionals as insiders within the alien hospital world.

Strengths and Limitations

There are a number of approaches that can be adopted in evaluating a grounded theory study. Glaser (1978) supported an approach which considered the fit, work, relevance and modifiability of the theory within the substantive area of the research. Charmaz (2006) has commented that these criteria are especially helpful for appraising how the theory translates the data collected and Glaser (2001) believed the criteria encapsulated all other quality benchmarks of qualitative research e.g. auditability, trustworthiness, confirmability and credibility. It is for these reasons that Glaser's evaluation criteria will be incorporated within the following evaluation of the strengths and limitations of this grounded theory study.

The main strengths of this study relate to the careful use of a grounded theory approach, collecting in-depth data to provide a detailed exploration of parental perspectives on their child's hospitalisation. The study employed a series of interviews with parents, enabling open and in-depth dialogue between parents and researcher. The resulting rich data uncovered several previously unexplored areas of parental experiences and perspectives. These areas included identification of key motivations for parental behaviours relating to their drive to continue parenting their child in hospital (as their protector and advocate); parents' transitional journey (from new parents to old hands); psycho-social processes occurring during their journey (searching for clues; judging and responding); escalation of parental signalling related to their

queries and concerns; parents' two views of care (at the time and on balance) and the recognition that parents' perceived care as high quality when health professionals acted as their allies in protecting and advocating for their child.

In addition, the use of constant comparative analysis techniques combined with opportunities to confer with parents throughout the development of the grounded theory further strengthened the study and ensured a close fit between the data and the final grounded theory. Glaser (1978) viewed the fit between data, categories and final theory as critical to the integrity of a grounded theory. In this study, examples from the data within the findings chapters demonstrate the clear links to category development through to the construction of the theory. The study design allowed the emergent theory to be checked out and refined through discussion with parents at the end of each interview. Parental recognition of components of the theory was reassuring as confirmation of the fit of the data to the theory.

In order for a grounded theory to 'work' in practice Glaser (1978) believed it should be able to explain, predict and interpret what occurs within the field of study. The theory of parenting in the alien world of the hospital provides some explanations for parental behaviours and responses when their child requires hospital care and also explains parents' apparent moderation and tolerance of less satisfactory events within care experiences. In doing this, the theory provides some new insights into the complex and previously poorly understood area of parents' quality evaluations in children's health care.

The theory demonstrates predictive qualities as it proposes that parental judgements of the quality of their child's care is influenced by the extent to which they perceive that health professionals are their allies in protecting and

advocating for their child. The theory also recognises that the lens through which the parents' judge care provision is individual and will be influenced by their previous life and hospital experiences, expectations, beliefs, values and their own personality but this lens will also be altered as they move from being 'new parents' to become 'old hands'.

Glaser (1978) commented that if a grounded theory is found to work in its area of practice then its relevance will naturally follow and can be expected. The novel and most relevant aspects of this theory for practice lie in the way that it lays out the experiences from the parents' perspective, identifies key influences on parental quality judgements and uncovers the use of parental signalling and the associated parental dilemmas. In considering this grounded theory's relevance there are a number of propositions detailed below to suggest how the theory does work and is relevant within the area of practice studied. The theory offers interpretations of the parental responses occurring within the experiences of their child requiring hospital care. These interpretations may assist health professionals to understand more fully parent - professional communications that occur when parents are searching and interpreting clues in the unfamiliar hospital environment. It is also proposed that, if health professionals appreciated early signals parents may give when they have a query or concern about care then more pro-active and effective information-giving could allay their anxieties early. It may also prevent escalation of parental signalling to the stages of 'saying something ' or 'doing something' and the inherent dilemmas and anxieties this incurs for parents. Furthermore a greater understanding of the clues that indicate to parents that the professionals are their allies in protecting and advocating for their child may help in focussing interactions that will be perceived more positively. Health professionals, armed

with this new knowledge, can alter their approaches to parents to further enhance the parents' experiences and perceptions of the quality of care provided.

Although the study presents important and unique contributions to existing empirical evidence in this field, the study's limitations also need to be considered. Initially, recruitment difficulties were experienced delaying commencement of the study, however, this did not have a detrimental impact on outcomes. To combat recruitment difficulties, specialist nurses were used, alongside ward nursing staff, to assist recruitment and this proved to be advantageous as it enabled parents of children with on-going conditions to be more readily recruited. To facilitate theoretical sampling within the study specialist nurses were asked at different points to invite participation from specific parent groups and this was guided by on-going constant comparative data analysis. Specialist nurses' involvement in identifying and approaching parents for recruitment may be viewed as a limitation, as nurses may have chosen to approach parents who they believed would provide positive assessments of staff and services. However, parents recruited from these services appeared to be candid in interviews providing both negative and positive accounts. In addition, it may not have been possible for nurses to really know which parents might be particularly positive in their evaluations.

The relatively small sample size in this study may be viewed as a limitation of the work. However, the diversity of the participants' experiences and the in-depth and rich data collected has enabled presentation of a substantive grounded theory providing new perspectives that challenge existing viewpoints

and offer opportunity to impact positively on practice. Larger studies to further explore these new perspectives may provide more details to the theory and extend or modify our understanding. Opportunity for future modification within a grounded theory, taking account of continually changing society and to extend and clarify elements of the original theory, is viewed as important in this research approach (Glaser, 1978). Similarly, Charmaz (2006) argues that detailed comparison of studies situated in their own context can lead to further abstract but at the same time general theories. Having initially constructed a substantive theory,

"from scrutinizing numerous particulars..." (p180)

she proposes that a formal theory can be constructed through analysis and conceptualisation of results of multiple studies situated in their own context. In this study there may be opportunity for future modifications enabling transfer to other 'alien worlds' that parents and children encounter or where individuals take on roles with similarities to that of a parent, for example, carers. Such explorations within a diverse range of settings and people could allow modification of the theory and thus the scope of its work beyond the limitations of this study.

This grounded theory is substantive meaning its parameters or 'workability' is limited to the substantive area studied and reflect characteristics of the sample. All families shared certain characteristics: parents were British, were employed and lived with the child. It would be valuable to explore the theory's utility with parents with a wider range of ethnic and socio-economic backgrounds. Similarly, further studies to explore parents' quality judgements where the

parents' 'on balance' judgement' of care remained poor may provide further important modifications to the theory. Whilst some parents in the sample had complained about an aspect of care no parents were actively engaged in an on-going complaint or remained unhappy with their child's care. A different picture may have been gathered with a sample of parents dissatisfied and unhappy with their experiences. However, gaining access to such a sample of parents may prove more challenging to recruit.

Further research would need to be undertaken to fully determine the theory's transferability to other settings and people. There may be a diverse range of 'alien worlds' where this theory may fit, for example, dementia care; elderly care; learning disability care and schools. In each of these 'worlds' there are key elements that bear similarities to this study setting, that is, an individual protecting and advocating for another, an alien nature to the world entered, power and dependency issues operating and high levels of concern for the individual's well-being.

What this study adds to current knowledge:

- Parents valued health professionals who demonstrated recognition of how frightening their child's hospitalisation was for them and the disruptions and tensions this entailed.
- Parents' behaviours were motivated by their need to protect and advocate for their child and they judged care as high quality when they perceived health professionals to be their 'allies' in these aspects of their parenting role.
- Parents' hospital experiences were characterised by landing; moving from being a 'new parent' to an 'old hand'; searching for and judging the

clues and facing dilemmas about how best to respond to health professionals

- Parents' personal lens, altered through their transitional journey and this, together with, their perception of the professionals' power impacted on their chosen responses to professionals and open expression of their quality judgements.
- Parents held two views of care, an 'at the time' and an 'on balance' view. The on-balance view was often a moderate view that took account of their heightened emotions, transition and changed personal lens. Parents also considered minimum acceptable standards within their 'on balance' view- was this a one-off situation? was any harm done? were the key needs of their child met?
- Parents' perceptions of the health professionals power impacted on their decisions when raising a query or concern. An escalating level of parental signalling has been identified whereby parents attempt to prompt responses from professionals: mentioning, asking, saying, doing, complaining.

Implications for policy, practice and education

Quality evaluations of health care, need to take account of complexities of parental judgement of care quality and factors controlling honest expression of these judgements. A reliance on satisfaction surveys to gain feedback is unlikely to fully uncover parents' experiences or provide opportunity for details

of what was valued or unwelcome in their experiences. Difficulties involved in capturing parents' views need to be acknowledged and addressed so that services can benefit from real positive and negative feedback that can be used to improve care. Positive re-enforcement to staff about elements of care provision that is highly valued by parents may not only lead to staff focussing on these effective strategies in their practice but may also boost staff morale.

Recognition that parents placed such high value on the feeling of having allies in the staff, rather than being alone, in their role as protector and advocate child is important. This needs to be recognised and reflected as a key aspect of care for families and incorporated in quality measures in this field and in education for children's nursing students. Professionals need to have time to effectively communicate with and support parents - recognising the overwhelming alien nature of this world. Recognition by professionals of parents' motivations in the way that they might communicate their concerns may enable them to avert complaints and concerns at an earlier stage. Quality measures and service improvements need to take account of parents' position within their experiences, appreciating that parents can almost feel like captives in the situation they find themselves. They may have little or no choice in remaining with service providers due to limited number of children's specialised services and this may impair their ability to provide honest views in satisfaction surveys resulting in falsely positive responses or superficial responses.

Parents' accounts showed moderation and tolerance of events that were less satisfactory to them 'at the time' demonstrating the need for any quality monitoring to be sensitive to the timing of such monitoring. Recognition of the wide zone of tolerance that exists for many parents as they take an 'on balance' overall view of their experiences needs to be taken into account in development

of quality monitoring programmes. Feedback mechanisms need to be in place and offer an easy and anonymous way for parents to feedback on their positive and negative experiences. In the absence of such mechanisms services are missing opportunities to focus on addressing negative aspects of provision whilst building on successful elements identified. This feedback loop may allow staff and managers to hear positive messages about good care rather than attention been mainly on addressing complaints.

There also needs to be recognition that in a large service such as the NHS, it is the people working in the service that can personalise care. For parents this was an important factor in their quality appraisals and does not necessarily require more staff. Health professionals need to appreciate the importance parents attach to this approach to care to foster positive relationships with families. Similarly, the importance of professionals' acting as an 'interpreter' for parents needs to be recognised as a critical aspect of family care. The value placed on staff who act in this role by parents means that deliberate, focused attention needs to be paid to this aspect of care to enhance parents' experiences and reduce their anxieties. Potential for parents to misunderstand or misinterpret clues could be diminished if this interpreter role was acknowledged and valued in children's nursing in a more prominent way. This work could easily be invisible within staff' workloads unless it is also valued by them as part of what distinguishes their work with children and families from other fields of nursing. Raising awareness amongst staff and student nurses of the need to recognise early signalling by parents that they have a query or concern could be highly beneficial. In addition to this, further enhancement of parental experience could be achieved through teaching staff and students strategies to employ to clearly and overtly demonstrate to families their

appreciation of how alien the hospital world may seem and to act as local guide, interpreter and ally to them. It is important that professionals explicitly communicate to parents that they are allies in protecting and advocating for their child and that their child's well-being matters to them too.

Recent developments and commitment to improvement of patient participation in health care is outlined in a publication from the Patients and Information Directorate NHS England (NHS England, 2013). This document details a range of strategies to improve patient participation in the NHS ensuring that patients' voices are heard and able to influence decisions at an individual to a national level across all age groups. The means by which patient feedback is obtained is identified and whilst still relying heavily on survey data, there is recognition of the need for alternative methods to ensure genuine feedback is obtained about services, which is encouraging.

Practitioners armed with the information from this study could improve their inter-actions with parents by fully recognising that the initial landing of new parents in the hospital world is a particularly frightening time. Parental need for information with meaning as well as emotional support at this critical time will reassure parents that they are not alone in their experiences and that they have allies in the staff. Professionals need to appreciate that even when parents do not raise a concern this does not necessarily mean they have evaluated care positively. Complex psycho-social dilemmas for parents when they consider "saying something" may prevent them from doing so as they weigh up the pros and cons for their child. Limited choice of services available to the families due to locations and centralisation of specialist services may also impact on parents' decisions about voicing any negative opinions. The potential risk that their comments may adversely affect their child's care or their relationship with staff

is a real one for parents and professionals need to understand parents' dilemmas.

Other strategies that practitioners could adopt to enhance care is to respond to parents signals of concerns early and provide interpretations for them to help their understanding of situations. In addition, to giving information that has meaning for parents and that addresses their 'next step' questions, staff need to ensure they allow time to check out parental understandings as well as invite 'at the time' feedback. There is potential to avert parents having 'to say something' or 'do something' or complain through recognition of the underlying motivation of the parents to protect and advocate for their child. Such escalation of their concern to having to say something is fraught with danger and dilemmas for parents as they try to judge the best approach and do not want to be labelled as a complainer. They are not always confident that this will be the best approach for their child and their on-going relationship with staff and services. However, if practitioners effectively communicated to parents that they were the parents' allies in keeping their child safe and ensuring their best interests were paramount then this may help reduce potential for conflict situations that occasionally arise.

Further advancement of feedback at ward and department level that is accessible, anonymous and welcomed may equally enhance services, provided that the feedback is acknowledged and acted upon. Finally, it is important that key messages from this study are fully disseminated through conference presentations (see Appendix 16) and publications to enable

professionals to use this new knowledge to help them improve families' experiences of hospital care.

Summary of implications for practice, policy and education

- Health professionals could improve parents' experiences and quality judgements of care by explicitly acting as parental allies.
- Health professionals could improve parents' experiences and quality judgements of care by early recognition and response to parental signalling, and this could prevent escalation of concerns to complaints.
- Health professionals, healthcare providers and policy makers need to develop more effective ways of gathering parental feedback than satisfaction surveys. Complex factors controlling expression of genuine parental views of care quality need to be recognised.
- Health professionals need to clearly demonstrate their empathy for parents landing in the alien hospital world and explicitly act as an ally to parents as they try to continue to parent their child in hospital.

Implications for future research

There are a number of directions in which it would be useful to further explore key findings from this study. Replication in other environments which may be viewed as 'alien' by parents could be important in extending our understanding of parental responses to situations involving their children. It is important to find out if the responses uncovered in this study are specific to parents when their

child requires hospital care or if these responses can be anticipated in other circumstances, for example, when a child starts nursery school. Enhancing knowledge and understanding in this area could assist professionals to be more effective in their future inter-actions and support of parents.

Through research studies with different patient groups outside of the parent and child dyad, important similarities and differences may be uncovered that could further modify and strengthen the theory. Different participant groups could include carers who take on protection and advocacy roles for others e.g. adults with a learning disability or dementia. Comparison of findings from these different groups with this study may demonstrate common approaches that could be useful to health professionals in practice. Further research in different settings may enable modification to this proposed grounded theory to develop it from a substantive to a formal theory.

Final Conclusions

At the outset of this study the central aim was to uncover information that would provide a better understanding of the ways that parents judged the quality of care provided when their child was hospitalised. Appreciation of parents' perspectives was prioritised in acknowledgement of their unique role whereby they had observed and experienced care for their own child. The central aim of the study has been achieved and the complexities and covert nature of parents' judgements and responses relating to quality of care were revealed. The direction of exploration was guided by parents' exposure of their dilemmas and decisions within quality judgements. New understandings of the complexities of

the psycho-social processes involved in parental judgements of quality have resulted in the construction of a substantive grounded theory of parenting in the 'alien' hospital world: 'on guard and on behalf'.

This study adds to existing evidence that patient surveys and questionnaires may not always reveal genuine views of service users including parents. Key psycho-social drivers influencing parents' potential responses within such feedback relate to the power of professionals and the system and parents' position of dependence alongside their loyalty and gratitude for their child's care.

An important contribution is made by this study's findings in uncovering the covert way that parents held their real views on care and the cautious manner in which some parents expressed their concerns to professionals. When faced with a query or concern varying levels of implicit and explicit parental signalling have been identified - 'asking-saying-doing-complaining'. Earlier recognition and appropriate responses by professionals may prevent further escalation of parental signals to the point of complaint, ensure parents' concerns are resolved and perhaps improve the parents' perception of the quality of the care provision.

Findings presented here further contribute to the knowledge base by identifying that parents' held two views on care: their 'at the time' view and their final 'on balance' view. Their final 'on balance' view took account of their heightened emotions at the time and their transition and change of personal lens as they moved from being a new parent to an old hand. The parents also considered their minimum standard of acceptable care within their 'on balance' view:- was

this a one -off situation? was any harm done? were the key needs of the child met?

The findings of this study demonstrate that whilst there are some similarities between customers, adult patients and parents of hospitalised children there are distinct differences in the way that parents make judgements about their child's hospital care. The distinctions are important and should be taken into account when implementing future quality service improvements. A key theme running throughout the findings was the strong parental need to continue 'parenting' (protecting and advocating) their child in hospital: the extent to which health professionals acted as their allies in these roles was a key determinant in parents' judgements of quality of care. Health professionals who behaved as allies to parents were prized as they were recognised as being powerful insiders within the alien hospital world.

In summary, parents judge hospital care as high quality when they perceive health professionals are their allies in their parenting roles, as protectors and advocates of their child, within the alien hospital world.

Critical Appraisal Skills Programme (CASP) Tool - qualitative studies

1. Was there a clear statement of the aims of the research?
2. Is a qualitative methodology appropriate?
3. Was the research design appropriate to address the aims of the research?
4. Was the recruitment strategy appropriate to the aims of the research?
5. Was the data collected in a way that addressed the research issue?
6. Has the relationship between researcher and participants been adequately considered?
7. Have ethical issues been taken into consideration ?
8. Was the data analysis sufficiently rigorous?
9. Is there a clear statement of the findings?
10. How valuable is the research?

Appendix 2

Critical review questions for quantitative studies (McMasters)

1. Was the purpose stated clearly? YES NO
Outline the purpose of the study. How does this study apply to your research question?
2. Was relevant background literature reviewed? YES NO
-Describe the justification of the need for this study.
3. Identify design: RCT/Cohort/Single case/Before and after/case-control/cross-sectional/case study
Describe the study design. Was the study design appropriate for the study question? Specify any biases that may have been operating and the direction of their influence on the results.
4. N=
 Was the sample described in detail? YES/NO
 Was the sample size justified? YES/NO N/A
Sampling (who; characteristics; how many; how was sampling done?) If more than one group, was there similarity between groups? Describe ethics procedures. Was informed consent obtained?
5. Were the outcomes measures reliable? YES/NO N/A
 Were the outcome measures valid? YES/NO N/A
Specify the frequency of outcome measurement i.e. (pre-post, follow up). List outcomes and measures.
6. Intervention was described in detail YES/NO
 Contamination was avoided YES/NO/not addressed/ N/A
 Co-intervention was avoided YES/NO/not addressed/N/A

Describe intervention (focus; who delivered it, how often, setting) Could the intervention be replicated in practice?

7. Results were reported in terms of statistical significance

YES/NO/not addressed/NA

Were the analysis methods appropriate?

YES/NO/not addressed

Clinical importance was reported

YES/NO/not addressed

Drop-outs were reported

YES/NO

8. Conclusions were appropriate given study methods and results

YES/NO

What did the study conclude? What are the implications for practice? What are the main limitations or biases in the study?

Law M., Stewart D., Pollock N., Letts L., Bosch J., and Westmorland M. Critical review form -quantitative studies. (www.srs-mcmaster.ca/research/evidence-based-practice-research-group, last accessed 20.12.15).

Appendix 3

Quality appraisal of qualitative studies - parents' perspectives

A scoring system was devised to provide numerical representation of the quality of papers reviewed. Scores were awarded according to responses to each questions within the critical appraisal tool: 0= not detailed/achieved; 1=partially detailed/achieved; 2= fully detailed/achieved. A summary of these quality appraisal scores is provided here in Appendices 3 and 4.

Paper	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Total
Avis M. and Reardon R. (2008)	2	2	2	1	2	1	2	1	2	2	17
Coyne I. and Cowley S. (2007)	2	2	2	1	2	1	1	2	2	2	17
Coyne I. (2006)	1	2	2	1	2	1	2	1	2	2	16
Coyne I. (2007)	2	2	2	2	2	1	1	2	2	2	18
Coyne I. (2015)	2	2	2	2	2	1	2	2	2	2	19
Dudley S.K. and Carr J.M. ,(2004)	2	2	2	1	2	1	0	2	2	2	16
Espezel H.J.E. and Canam C.J., (2003)	2	2	2	2	2	1	2	1	2	2	18
Higham S. and Davies R. , (2012)	2	2	2	2	2	1	1	2	2	2	18
Peeler A. et al (2015)	2	2	2	2	2	1	2	2	2	2	19
Sartain S. et al (2001)	2	2	2	2	2	1	1	2	2	2	18
Stratton K. (2004)	2	2	2	1	2	1	1	2	2	2	17
Tong A. et al (2010)	2	2	2	2	2	1	1	2	2	2	18

Quality appraisal of qualitative studies - children's perspectives

Paper	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Total Score
Brady M. (2009)	2	2	2	2	2	1	2	1	2	2	18
Carney T. et al (2003)	2	2	2	1	1	2	2	1	2	2	17
Coyne I. (2006)	1	2	2	1	2	1	2	1	2	2	16
Coyne I. (2015)	2	2	2	2	2	1	2	2	2	2	19
Coyne I. and Gallagher P. (2011)	2	2	2	2	2	1	2	2	2	2	19
Coyne I. and Kirwan L. (2012)	2	2	2	2	1	1	1	2	2	2	17
Fletcher T. et al (2011)	2	2	2	2	2	1	1	2	2	2	18
Ford K. (2011)	1	2	2	2	2	1	2	1	2	2	17
Hallström I. and Elander G. (2004)	2	2	2	1	1	2	2	2	2	2	18
Lambert V. et al (2013)	2	2	2	2	2	1	1	2	2	2	18
Lambert V. et al (2012)	2	2	2	2	2	1	2	2	2	2	19
Lambert V. et al (2014)	2	2	2	2	1	1	2	2	2	2	18
Pelander T. and Leino-Kilpi H. (2004)	2	2	2	1	2	1	1	1	2	2	16

Quality appraisal of qualitative studies - children's perspectives continued

Pelander T. and Leino-Kilpi H. (2010)	2	2	2	2	2	1	2	2	2	2	19
Sartain S. et al (2000)	2	2	2	1	2	2	2	2	2	2	19
Smith L. and Callery P. (2005)	2	2	2	1	2	1	2	2	2	2	18

Quality appraisal of qualitative studies - health care professionals' perspectives

Paper	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Total Score
Coyne I. and Cowley S. (2007)	2	2	2	1	2	1	1	2	2	2	17
Coyne I. (2006)	1	2	2	1	2	1	2	1	2	2	16
Coyne I. (2007)	2	2	2	2	2	1	1	2	2	2	18
Coyne I. (2015)	2	2	2	2	2	1	2	2	2	2	19
Higham S. and Davies R. , (2012)	2	2	2	2	2	1	1	2	2	2	18
Paliadelis P. et al (2005)	2	2	2	2	2	1	2	2	2	2	19
Panicker L. (2013)	2	2	2	2	2	1	1	2	2	2	18
Peeler A. et al (2015)	2	2	2	2	2	1	2	2	2	2	19
Ygge B.M. (2007)	2	2	2	1	1	1	2	1	2	1	15

Quality appraisal of quantitative studies - parents' perspectives

Appendix 4

A scoring system was devised to provide numerical representation of the quality of papers reviewed. Scores were awarded according to responses to each questions within the critical appraisal tool: 0= not detailed/achieved; 1=partially detailed/achieved; 2= fully detailed/achieved. A summary of these quality appraisal scores is provided here in Appendices 3 and 4.

Paper	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Total
Ammentorp J. et al (2006)	2	2	2	1	2	1	2	2	14
Burns-Nader S. et al (2014)	2	2	2	1	2	1	1	2	13
Byczkowski T.L. et al (2013)	2	2	2	1	1	1	2	2	13
Chesney et al (2005)	2	2	2	1	1	1	2	2	13
Cox E.D. et al (2012)	2	2	2	1	2	1	2	2	14
Co J.P. et al (2003)	2	2	2	1	2	1	1	2	13
Hughes M., (2007)	2	2	2	2	2	1	1	2	14
Matziou V. et al, (2011)	2	2	2	1	2	1	2	2	14
Miceli P.J. and Clark P.A. (2005)	2	1	2	1	2	1	2	2	13
Phua V. et al (2005)	2	1	2	1	2	1	2	2	13
Shields L. et al (2004)	2	2	2	2	2	1	2	2	15
Simons J. (2002)	2	2	2	1	2	1	2	2	14

Solheim E. and Garrett A.M. (2013)	2	2	2	1	2	1	2	2	14
Williams G. et al (2011)	2	2	2	1	2	1	2	2	14
Wray J. et al (2011)	2	2	2	2	2	1	2	2	15

Quality appraisal of quantitative studies - children's perspectives

Paper	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Total Score
Chesney et al (2005)	2	2	2	1	1	1	2	2	13
Pelander T. et al, (2007)	2	2	2	2	2	1	2	2	15

Quality appraisal of quantitative studies - health care professionals' perspectives

Paper	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Total Score
Hughes M., (2007)	2	2	2	2	2	1	1	2	14
Shields L. et al (2004)	2	2	2	2	2	1	2	2	15
Simons J. (2002)	2	2	2	1	2	1	2	2	14
Ygge B.M. et al, (2006)	2	2	2	2	2	1	2	2	15

APPENDIX 5

Characteristics of studies reviewed - parents ' perspectives

Author(s) and date	Title	Location	Sample	Type of hospital experience or child's condition
Ammentorp J., Mainz J. and Sabroe S. (2006)	Determinants of priorities and satisfaction in pediatric care.	Denmark	300 parents of children admitted to hospital	Acute and planned general in-patient admissions.
Avis M. and Reardon R. (2008)	Understanding the views of parents of children with special needs about the nursing care their child receives when in hospital: a qualitative study.	UK	12 parents of children with special needs	Children with special needs admitted for acute hospital care
Byczkowski T.L. et al (2013)	A comprehensive view of parental satisfaction with pediatric emergency department visits.	USA	2442 parents	Parents of children who had attended the emergency department.
Chesney et al (2005)	Comparison of child and parent satisfaction ratings of ambulatory pediatric subspecialty care	USA	116 children and adolescents 115 parents	Children and their parents who had experience of care at two pediatric subspecialty clinics.
Cox E.D. et al (2012)	Parent perceptions of children's hospital safety climate.	USA	172 parents	Parents of children hospitalised with acute and chronic illnesses.
Coyne I. and Cowley S. (2007)	Challenging the philosophy of partnership with parents: a grounded theory study	UK	11 children; 10 parents and 12 nurses	Parents of children hospitalised in surgical and medical wards.
Coyne I. (2006)	Consultation with children in hospital: children, parents' and nurses' perspectives	UK	33 participants: 11 children 10 parents and 12 nurses	Children were in-patients with chronic conditions; skin conditions and orthopaedic conditions.

Coyne I. (2007)	Disruption of parent participation: nurses' strategies to manage parents on children's wards.	UK	12 nurses	Nurses from 4 paediatric wards in England where children had acute and chronic illness.
Coyne I. (2015)	Families and health-care professionals' perspectives and expectations of family-centred care: hidden expectations and unclear roles,	Ireland	18 children; 18 parents of the child participants; 18 nurses	General medical and surgical hospital experiences. Three hospital sites.
Co J.P. et al (2003)	Are hospital characteristics associated with parental views of pediatric inpatient care quality?	USA	6030 parents	Parents of children hospitalised with a medical condition.
Dudley S.K. and Carr J.M. (2004)	Vigilance: the experience of parents staying at the bedside of hospitalized children.	USA	10 parents	Parents who stayed at the bedside of their hospitalised children.
Espezel H.J.E. and Canam C.J., (2003)	Parent-nurse interactions: care of hospitalized children.	Canada	8 parents	Parents of children who attended ambulatory clinics following prematurity or neonatal critical illness.
Higham S. and Davies R. (2012)	Protecting, providing and participating: fathers' roles during their child's unplanned hospital stay, an ethnographic study.	UK	12 fathers and 7 children's nurses	Fathers of children who had unplanned admission to general paediatric hospital ward.
Hughes M., (2007)	Parents' and nurses' attitudes to family-centred care: an Irish perspective.	Ireland	100 parents and 44 nurses	Parents who had stayed overnight in a paediatric unit with their hospitalised child.
Matziou V. et al, (2011)	Parents' satisfaction concerning their child's hospital care.	Greece	206 parents	Parents of children hospitalized in two pediatric and two surgical units.

Miceli P.J. and Clark P.A. (2005)	Your patient- my child	USA	50,446 parents	Parents of children treated at 65 US hospitals.
Peeler A. et al (2015)	The experiences of parents and nurses of hospitalised infants requiring oxygen therapy for severe bronchiolitis: A phenomenological study.	Australia	12 mothers and 12 nurses	Mothers of infants admitted with bronchiolitis requiring oxygen therapy.
Phua et al (2005)	Inpatient care of children with cerebral palsy as perceived by their parents.	Australia	40 parents of children with cerebral palsy and 90 parents of able-bodied children	Mothers of children who had an inpatient admission.
Sartain S. et al (2001)	Users' views on hospital and home care for acute illness in childhood.	UK	40 families (11 children)	Parents of children who had either been admitted to hospital or had hospital at home care for an acute minor illness.
Shields L. et al (2004)	Parents' and staff's perceptions of parental needs during a child's admission to hospital: An English perspective.	UK	85 parents and 73 health professionals	Parents of children who had unplanned acute admission to hospital with acute or chronic illnesses.
Simons J. (2002)	Parents' support and satisfaction with their child's post-operative care.	UK	20 parents and 20 nurses	Parents of children who had undergone surgical procedures.
Solheim E. and Garrett A.M. (2013)	Parent experiences of inpatient pediatric care in relation to health care delivery and socio-demographic characteristics: results of a Norwegian national survey.	Norway	3,308 parents	Parents of children admitted to one of Norway's 20 pediatric departments.

Stratton K. (2004)	Parents' experiences of their child's care during hospitalization.	USA	6 parents	Parents who had stayed with their child each day when their child was in hospital.
Tong A. et al (2010)	Parental perspectives on caring for a child with chronic kidney disease: an in-depth interview study.	Australia	20 parents	Parents of children with chronic kidney disease.
Williams G. et al (2011)	Improving parental satisfaction in pediatric orthopaedics.	UK	104 parents	Parents of children admitted for paediatric orthopaedic care (elective or trauma admissions).
Wray J. et al (2011)	Parental anxiety and stress during children's hospitalisation: The StayClose study.	UK	Parents of 28 children.	Parents of children hospitalised for at least three days mainly for surgery with a range of diagnoses (cancer, cerebral palsy, heart defects).

Characteristics of studies reviewed - children's perspectives

Author(s)	Title	Location	Sample	Type of hospital experience or child's condition
Brady M. (2009)	Hospitalized children's views of the good nurse	UK	22 children	Children were in-patients of a paediatric unit in England.
Carney T. et al (2003)	Children's views of hospitalization: an exploratory study of data collection	UK	213 children. Patients from paediatric wards of two district general hospitals	Children admitted to hospital within the following treatment categories: medical, orthopaedics, surgical, maxillofacial, plastic surgery and ENT.
Chesney et al (2005)	Comparison of child and parent satisfaction ratings of ambulatory pediatric subspecialty care	USA	116 children and adolescents 115 parents	Children and their parents who had experience of care at two pediatric subspecialty clinics
Coyne I. (2006)	Consultation with children in hospital: children, parents' and nurses' perspectives	UK	33 participants: 11 children 10 parents and 12 nurses	Children were in-patients with chronic conditions; skin conditions and orthopaedic conditions.
Coyne I. (2006)	Children's experiences of hospital	UK	11 children	In-patient experience. Children (n=8) had chronic conditions i.e. asthma, orthopaedic and skin conditions and some children (n=3) had acute conditions i.e. cellulitis, constipation, deep vein thrombosis.
Coyne I. (2015)	Families and health-care professionals' perspectives and expectations of family-centred care: hidden expectations and unclear roles,	Ireland	18 children; 18 parents of the child participants; 18 nurses	General medical and surgical hospital experiences. Three hospital sites.
Coyne I. and Gallagher P. (2011)	Participation in communication and decision-making: cyp's experiences in a hospital setting	Ireland	55 children and young people (age 7-18)	Children with hospital experience with acute and chronic illnesses.

Coyne I. and Kirwan L. (2012)	Ascertaining children's feelings about hospital life	UK	55 children	Children with acute (n=27) and chronic illnesses (n=28) with in-patient experience from two children's hospitals and one district general hospital.
Fletcher T. et al (2011)	Building the future: children's views in nurses and hospital care	UK	61 children: hospital patients (n = 53) and members of the city youth parliament (n=8).	Children (n=53) with in-patient experiences within two children's hospitals and 8 children from the city youth parliament.
Ford K. (2011)	'I didn't really like it, but it sounded exciting': Admission to hospital for surgery from the perspectives of children	Australia	10 children	Children who had been admitted to hospital for planned and unplanned surgery
Hallström I. and Elander G. (2004)	Decision-making during hospitalization: parents' and children's involvement	Sweden	24 children and parents	Children admitted to hospital electively or unplanned. Various diagnoses excluding life-threatening illness.
Lambert V. et al (2013)	Social spaces for young children in hospital	UK	55 children	Children selected from in-patient; outpatient; emergency and day units of three children's hospitals.
Lambert V. et al (2012)	Meeting the information needs of children in hospital	UK	49 children	Children with a variety of medical and surgical conditions admitted to one children's ward in a children's hospital.
Lambert V. et al (2014)	Young children's perspectives of ideal physical design features for hospital built environments	UK	55 children	Children selected from in-patient; outpatient; emergency and day units of three children's hospitals.
Pelander T. and Leino-Kilpi H. (2004)	Quality in pediatric nursing care: children's expectations	Finland	40 children (20 pre-school and 20 school aged)	Children with insulin dependent diabetes mellitus and children with experience of admission to a surgical ward.

Pelander T. et al (2007)	Quality of pediatric nursing care in Finland	Finland	388 children	Children aged 7-11 years with experience of admission to pediatric medical or surgical wards in five hospitals in Finland.
Pelander T. and Leino-Kilpi H. (2010)	Children's best and worst experiences during hospitalisation	Finland	388 children	Children aged 7-11 years with at least overnight hospital admission experience.
Sartain S.A. et al (2000)	Hearing the voices of children with chronic illness	UK	24 participants: 6 children, 7 nurses, 11 parents	Children with chronic conditions i.e. cystic fibrosis; asthma; abdominal pain; migraine and Rett's syndrome.
Smith L. and Callery P. (2005)	Children's accounts of their preoperative information needs	UK	9 children aged 7-11 years	Children admitted to hospital for surgery

APPENDIX 7

Characteristics of studies reviewed - health professionals' perspectives

Author(s) and date	Title	Location	Sample	Type of experience or child's condition
Coyne I. (2006)	Consultation with children in hospital: children, parents' and nurses' perspectives	UK	33 participants: 11 children 10 parents and 12 nurses	Nurses worked in 4 children's wards within 2 hospitals. The children were in-patients with chronic conditions; skin conditions and orthopaedic conditions.
Coyne I. (2007)	Disruption of parent participation: nurses' strategies to manage parents on children's wards.	UK	12 nurses	Nurses from 4 paediatric wards in England where children had acute and chronic illness.
Coyne I. (2015)	Families and health-care professionals' perspectives and expectations of family-centred care: hidden expectations and unclear roles,	Ireland	18 children; 18 parents of the child participants; 18 nurses	General medical and surgical hospital experiences. Three hospital sites.
Coyne I. and Cowley S. (2007)	Challenging the philosophy of partnership with parents: a grounded theory study	UK	11 children; 10 parents and 12 nurses	Nurses from 4 medical/surgical paediatric wards in two hospitals.
Higham S. and Davies R. , (2012)	Protecting, providing and participating: fathers' roles during their child's unplanned hospital stay, an ethnographic study.	UK	12 fathers and 7 children's nurses	Qualified nurses working on two children's wards of a district general hospital in UK.

Hughes M., (2007)	Parents' and nurses' attitudes to family-centred care: an Irish perspective.	Ireland	100 parents and 44 nurses	Qualified nurses from the paediatric unit from staff nurse to clinical nurse manager level.
Paliandelis P. et al (2005)	Implementing family-centred care: An exploration of the beliefs and practices of paediatric nurses.	Australia	14 paediatric nurses	Paediatric nurses who care for hospitalised children in paediatric wards of two hospitals. Nurses had a diverse range of experience.
Panicker L. (2013)	Nurses' perceptions of parent empowerment in chronic illness.	Australia	14 child health nurses.	Registered nurses who work with children with chronic illness.
Peeler A. et al (2015)	The experiences of parents and nurses of hospitalised infants requiring oxygen therapy for severe bronchiolitis: A phenomenological study.	Australia	12 mothers and 12 nurses	Paediatric nurses working in the paediatric unit with between 2 and 25 years experience.
Shields L. et al (2004)	Parents' and staff's perceptions of parental needs during a child's admission to hospital: An English perspective.	UK	85 parents and 73 health professionals	The staff that participated consisted of the nurses, doctors and allied health staff who had cared for the children and families invited to participate in the study.
Simons J. (2002)	Parents' support and satisfaction with their child's post-operative care.	UK	20 parents and 20 nurses	Nurses were matched to the parent who had been interviewed about their child's postoperative care.

Ygge B.M. (2007)	Nurses' perceptions of parental involvement in hospital care.	Sweden	Experienced (n=7) and newly qualified nurses (n=6)	Qualified nurses working in a paediatric university hospital with diverse specialities e.g. surgery; oncology; neonatal; orthopaedics; neurology and intensive care.
Ygge B.M. et al (2006)	Hospital staff perceptions of parental involvement in paediatric hospital care.	Sweden	207 paediatric hospital staff	Paediatric hospital staff - physicians; Registered Nurses and nursing auxiliaries working on oncology, surgery and neurology units in three children's hospitals.

Design of studies reviewed - parents' perspectives

Author(s)	Purpose of study	Recruitment of Sample	Methods	Key Findings
Ammentorp J., Mainz J. and Sabroe S. (2006)	To investigate determinants of parents' priorities and satisfaction in relation to pediatric inpatient care and to examine the relationship between fulfilment of expectations and satisfaction.	Convenience	Quantitative descriptive survey - two self-administered questionnaires on admission and post-discharge. Mainly Likert scales with some open-ended questions. Data analysed using descriptive statistics and thematic analysis of qualitative responses.	Determinants of above average satisfaction scores were: confidence in doctors; parents' questions being answered about care and treatment; satisfaction with the nurses' and doctors' behaviour. Waiting time was a weak determinant although it was given the highest priority score.
Avis M. and Reardon R. (2008)	Views of parents about the nursing care their child with special needs received during a hospital admission.	Purposive	Qualitative study. Interviews. Thematic analysis.	Parents experience some difficulties in developing trusting relationships with nurses; perceive nurses are not always able to recognise and respond to their needs when caring for their child. Failure to address these needs can interfere with the development of effective nurse-parent relationships.
Byczkowski T.L. et al (2013)	Parental satisfaction with pediatric emergency department visits.	Random sampling	Telephone survey. Measures: adapted questions from satisfaction rating scale Consumer Association of Health Care Providers and Systems Survey and Picker Institute. Quantitative data analysed using multivariate analysis to	Parental satisfaction best predicted by how well health professionals were perceived to work together; waiting times and pain management. Parents perceptions of staff working together were influenced by doctors and nurses sharing

Byczkowski T.L. et al (2013) - continued			predict outcomes. Thematic content analysis undertaken for qualitative responses.	information; detailed explanations given to parents; parents not having to repeatedly answer the same questions. Other potential key satisfiers: courteous and respectful staff - demonstrated through caring and compassionate words and behaviours; paying attention to non-medical needs. Using qualitative data to augment and clarify qualitative findings is essential to obtain a full picture of aspects of emergency care important to parents.
Chesney et al (2005)	To compare child and parent satisfaction ratings of ambulatory pediatric subspecialty care	Convenience	Quantitative study- Measures: Satisfaction with Child Healthcare Survey adapted from Kids Counts Survey (McMasters) + open ended questions. Descriptive statistics and comparisons of scores between groups. Thematic analysis of qualitative data.	Moderate significant correlation between child and parent scores. Parents rated care more highly than children. Children's responses varied in the open questions on various aspects of care. Parents evaluations of care may not accurately reflect the views of children.
Cox E.D. et al (2012)	To identify parental perceptions of children's hospital safety climate.	Convenience	Quantitative study - Measures:- survey about hospital safety climate and perceived need to watch over their child's care. Statistical analysis used confirmatory factor analysis and logistic regression to validate safety domain measures and then relate 'need to watch over care' to safety climate domains.	39% of parents agreed they needed to watch over care. The need to watch over care was significantly related to overall perceptions of safety ; handoffs and transitions but not to openness of staff or parent communication.

Coyne I. and Cowley S. (2007)	Views of children, parents and nurses on participation in care in hospital.	Purposive Sampling	Qualitative study using grounded theory. Interviews and observational data collected. Constant comparative analysis of data.	Nurses saw their role as care facilitators and assumed parents would participate in care. Parent-nurse relationships not real partnerships; parents felt obliged to be present and felt responsible for hospital care. Nurses relied on parents to contribute to care.
Coyne I. (2006)	Views of children, parents and nurses on participation in care in hospital.	Purposive sampling	Qualitative study using grounded theory. Interviews, questionnaires and observations. Constant comparative analysis.	Parents and children thought children should be involved in decision-making. Children wanted to be consulted/ informed so that - involved and self-preparation. Professionals communication behaviours reflected child's cognitive ability rather than level of understanding. Nurses views discrepant and involvement of children in decisions made without framework.
Coyne I. (2007)	To investigate parental participation in care from the perspectives of children, parents and nurses.	Purposive sampling	Qualitative study using grounded theory. Interviews, questionnaires and observation. Constant comparative analysis.	Parents socialised by inclusionary and exclusionary tactics. Nurses controlled parental participation. Expectations of parents were to stay, be involved and behave. Parents not adhering to norms caused ward disruption. Compliance or non-compliance to rules - rewarded or punished. Nurses depended on parental participation -driver not necessarily empowerment.

Coyne I. (2015)	To examine family centred care from child, parent and nurse perspectives.	Purposive	Descriptive qualitative study - interviews with children, parents and nurses. Constant comparative analysis.	Nurses positive re: family centred care and rely on families to support care. Families willing to support child's care but greater clarity needed about role and information/support to avoid stress. Delivery of FCC requires resources, management support and nursing skills.
Co J.P. et al (2003)	Are hospital characteristics associated with parental views of pediatric inpatient care quality?	Convenience	Quantitative study - cross sectional analysis of hospital surveys. Picker Institute's Pediatric Inpatient Survey. Correlations were reported between overall quality scores and dimensions of inpatient care scores.	High subjective ratings were recorded for quality of care but specific dimensions of care scores reveal variations. Improving the quality of communication with parents may have the most positive impact on a hospital's overall quality of care rating.
Dudley S.K. and Carr J.M. ,(2004)	Vigilance: the experience of parents staying at the bedside of hospitalized children.			
Espezel H.J.E. and Canam C.J., (2003)	To examine parents' experiences of interacting with nurses in hospital about their child's care.	Purposive	Qualitative study. Interviews. Thematic analysis of data.	Establishing rapport and sharing care perceived positively by parents within interactions with nurses. Perceptions influenced by parents expectations of nurses. Nurses' approach perceived to change as child's condition changed. Parents did not view interactions as collaborative relationships.

Higham S. and Davies R. , (2012)	To understand fathers' experiences of their child's unplanned hospital stay with acute illness or injury.	Purposive	Ethnographic study. Participant observation and interviews. Data analysed using open coding and interpretation.	Three aspects of the fathers' role were: protecting, providing for the family and participation in care. Fathers wanted to 'be with' and care for child but faced challenges in balancing responsibilities at work and caring for well siblings. Professionals need to take account of fathers' roles.
Hughes M., (2007)	To explore parents' and nurses' attitudes to family-centred care.	Random	Quantitative descriptive study. Questionnaires using closed questions, Likert scales. Data analysed using SPSS.	No major differences found between nurses' and parents' attitudes towards family-centred care. Differences between how nurses and parents viewed their roles. Parents felt they needed to stay because nurses too busy but nurses did not think this was why parents stayed. Many parents did not know what was expected of them. Both groups agreed need improved facilities for parents.
Matziou V. et al, (2011)	To explore parents' satisfaction with their child's hospital care.	Not fully described	Quantitative study - descriptive, non-experimental correlation study. Measures: interviews based on the Swedish Pyramid Questionnaire. Descriptive statistical analysis and multiple regression through SPSS.	Parents most satisfied with staff attitudes and treatment and less satisfied with information about routines and work environment. Adequate care; pain management, parental involvement in care, trusting relationships and staff attitudes key determinants of parental satisfaction.

Miceli P.J. and Clark P.A. (2005)	To describe parents' satisfaction with the experience of their child's hospitalisation and identify potential areas for improvements.	Convenience	Quantitative study - retrospective data from national survey. Measure:- Press Ganey Pediatric Inpatient Survey®. Likert-type scale responses. Descriptive statistics..	Parents overall satisfaction scores good/very good. Issues most important to parents were: staff sensitivity to disruption hospitalisation causes; emotional/spiritual family needs; parental inclusion in decision-making; environment - visitors; information about facilities for families; making child's stay restful.
Peeler A. et al (2015)	To describe parents' and nurses' experiences of infants' hospitalisation for severe bronchiolitis requiring oxygen therapy.	Purposive	Qualitative study. Descriptive phenomenology. Interviews. Colaizzi's approach to data analysis followed.	Mothers extremely fearful that child may die. Lacked knowledge and understanding and ability to fulfil mothering role increased anxieties. Nurses did not fully appreciate the extent of the mothers' fears and tended to focus on procedure aspects of their role. Mothers' emphasis was on physical contact with child and providing comfort. Nurses' focus was on health and safety aspects of care for child and themselves.
Phua et al (2005)	To evaluate inpatient care of children with cerebral palsy (CP) as perceived by their parents.	Convenience	Quantitative study- cross sectional study. Parents of children with CP (Cases) and parents of other children (controls).Satisfaction Questionnaire and Perceived Stress Scale. Data analysed using STATA 8.	Parents of able-bodied children more satisfied overall with hospitalisation than parents of children with CP. Significant differences found with satisfaction in admission process; child's care; communication/ confidence in staff and personal hospital experience. Parents of children with CP higher scores on perceived stress scale.

Sartain S. et al (2001)	Users' views on hospital and home care for acute illness in childhood.	Purposive	Qualitative element of a larger Randomised Controlled Trial. Parent interviews and Children's drawings and interviews. Content analysis of data.	Majority of parents (90%) preferred 'hospital at home' care to hospital admission where illness was manageable with professional support at home. Social and financial costs additional factors in decisions rather than care quality.
Shields L. et al (2004)	To compare parents' and staff's perceptions of parental needs during a child's admission to hospital.	Convenience	Quantitative study. Measures: modified versions of the Needs of parents of hospitalized children questionnaire (NPQ). Data analysed using SPSS allowing comparisons between groups and categories.	Some differences between parental and staff perceptions of importance of parental needs and fulfilment of needs but no consistent patterns found. Parents reported themselves more independent than staff perceived them to be.
Simons J. (2002)	To explore parents' support and satisfaction with their child's post-operative care.	Convenience	Mixed methods study Quantitative study. Measures: survey; Nurse Parent Support Tool (NPST); patient charts. Qualitative study. Interviews.	Nurses perceptions of the level of support they were providing to parents was higher than that the level of support parents perceived they received. Parents more satisfied with pain management when child cared for by lower grade nurse and child received more analgesia.
Solheim E. and Garrett A.M. (2013)	Parent experiences of inpatient pediatric care in relation to health care delivery and socio-demographic characteristics: results of a Norwegian national survey.	Convenience	Quantitative study - national survey including Parent Experience of Pediatric Care Questionnaire. Descriptive statistics presented and data analysed using OLS-regression.	Children's pain relief, unexpected waiting, disappointment with staff, information about new medication, incorrect treatment and number of previous admissions were associated with parental ratings of their experiences. Parents experiences did not vary much by socio-demographic characteristics.

Stratton K. (2004)	To explore parents' experiences of their child's care during hospitalization.	Convenience	Qualitative study -grounded theory. Interviews. Data analysed by constant comparative analysis.	Four processes were identified ; - facing boundaries, attempting to understand, coping with uncertainty, seeking reassurance from care givers. Parents use the parent-caregiver relationship to help cope with their child's condition and this in turn influences the parents' sense that their and their child's needs are being met.
Tong A. et al (2010)	To explore the parents experiences of caring for a child with chronic kidney disease.	Purposive	Qualitative study - interviews. Thematic analysis used.	Four themes identified:- absorbing the clinical environment; medicalizing parenting; disrupting family norms; coping strategies and support.
Williams G. et al (2011)	To identify areas of inpatient pediatric orthopaedic care for improvement to potentially increase parental satisfaction.	Convenience	Quantitative study - Measures: Swedish Parent Satisfaction Questionnaire.	Overall highest scores were for parents perceptions of medical treatment (staff skill and competence) and staff attitudes. Lowest scores related to information on routines (ward rounds; identification of staff caring for child and who questions could be directed to about their child). Improving information provision was most likely to improve future parental satisfaction with care.

Wray J. et al (2011)	Parental anxiety and stress during children's hospitalisation: The StayClose study.	Purposive	Quantitative study - questionnaires completed at three time points. Instruments used :- Hospital Anxiety and Depression Scale; Brief COPE; Duke Functional Social Support Questionnaire; Life Orientation Test -revised; Parent Stressor Scale: Child hospitalisation; Parent perception of uncertainty in illness; Impact of events scale -revised. Open questions included with discharge and post-discharge questionnaires.	Parents experience considerable stress and anxiety when their child is hospitalised. Almost 2/3 of parents scored borderline/clinical range for anxiety at baseline and discharge. Higher anxiety scores were associated with maladaptive coping strategies; higher levels of uncertainty related to child's illness and a greater number of previous admissions.
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Design of studies reviewed - children's perspectives

Author (s)	Purpose of study	Recruitment of sample	Methods	Key findings
Brady M. (2009)	To explore views of hospitalized children of the good nurse	Convenience	Qualitative - grounded theory. Interviews using adapted draw and write technique.	Children's views of the good nurse - themes identified - communication; professional competence; safety; professional appearance; and virtues.
Carney T. et al (2003)	To investigate children's views of hospitalization.	Convenience	Qualitative - four different types of questionnaires (draw and write). Data analysed thematically. QSR NUD*IST Vivo.	Mainly positive feedback - environment frequently commented upon as well as familiar aspects of home life -games, food, TV. Younger children and continuity of caregiver important.
Chesney et al (2005)	To compare child and parent satisfaction ratings of ambulatory paediatric care	Convenience	Quantitative study- Measures: Satisfaction with Child Healthcare Survey adapted from Kids Counts Survey (McMasters) plus some open ended questions included. Descriptive statistics calculated and comparisons of scores between groups. Thematic analysis of qualitative data.	Moderate significant correlation between child and parent scores. Parents rated care more highly than children. Children's responses varied in the open questions on various aspects of care. Parents evaluations of care may not accurately reflect the views of children.

Coyne I. (2006)	To explore children, parents' and nurses' perspectives on participation in care.	Not fully described	Qualitative study. Grounded theory. Interviews, observations and questionnaire. Data analysed by constant comparative analysis.	Parents felt it helpful for children's self-esteem; positive self regard and welfare for children to be involved in decision-making. Children wanted consultation and information so that they could understand illness; be involved in care and prepare themselves for procedures. Experiences of consultation varied. Opinions under-utilised. Nurses views varied on children's involvement in decisions and sometimes dependent on child's cognitive maturity.
Coyne I. and Gallagher P. (2011)	To explore children and young people's experiences of participation in communication and decision-making.	Purposive	Qualitative study. Focus groups and individual interviews. Data analysed using codes, categories and themes. Nvivo 2 used in analysis.	Communications were mainly between professionals and parents though children wanted inclusion played marginal role. Children wanted to make small decisions about care and treatment but constrained by adults behaviours.
Coyne I. and Kirwan L. (2012)	To explore children's wishes and feelings about hospital life	Not fully described	Qualitative study. Interviews with use of child-specific participatory techniques. Content analysis to code/categorise data.	Both negative and positive views of hospital and health professionals were expressed. Causes of dissatisfaction :- lack of information, involvement and play facilities. Children wanted to express views, ask questions and be better informed about care/treatment. Wanted professionals to listen more and take their views into account.
Coyne I. (2006)	To explore children's experiences of hospital	Not fully described	Qualitative study-grounded theory. Interviews. Data analysed with Filemaker Pro 1992. Codes and categories developed.	Children identified many fears about hospital :- separation - parents/ family; unfamiliar surroundings; clinical procedures, treatments and loss of self-determination. Loss of self-determination increases fears/ concerns. Children need information; involvement in care and more child-friendly environments.

Coyne I. (2015)	To examine family centred care from child, parent and nurse perspectives.	Purposive	Descriptive qualitative study - interviews with children, parents and nurses. Constant comparative analysis.	Nurses positive re: family centred care and rely on families to support care. Families willing to support child's care but greater clarity needed about role and information/support to avoid stress. Delivery of FCC requires resources, management support and nursing skills.
Fletcher T. et al (2011)	To explore the views of children and young people about nurses and hospital care	Convenience and purposeful sampling	Qualitative study - draw and write/tell techniques	Future nurses need to have verbal and non- verbal communication and clinical skills. Children are scared and worried about admission to hospital - fear of the unknown once admitted their concerns centre on the care environment; social needs and personal needs and requirements.
Ford K. (2011)	To explore children's experiences of admission to hospital for surgery.	Purposive	Qualitative study. Constructivist grounded theory. Interviews; observations; 'draw and write' techniques. Data analysed by constant comparative analysis.	Substantive theory developed - children's reframing of their sense of selves to incorporate the experiences of hospitalization and surgery. Children need information and support to help them overcome their fears and anxieties around surgery.
Hallström I. and Elander G. (2004)	To explore what kind of decisions and how decisions made during child's hospitalisation.	Purposive	Qualitative study. Non-participation observation. Manifest and latent coding used to analyse data.	Mostly medical decisions involved. Generally decisions made in consultation with those affected by decision. Decisions seldom reconsidered when there was dissent.

Lambert V. et al (2013)	Social spaces for young children in hospital	Purposive	Qualitative study. Interviews - one to one and workshops (with participatory art-based activities). Thematic content analysis.	Young children want a diversity of readily available, independently accessible, age, gender and developmentally appropriate leisure and entertainment facilities seamlessly integrated throughout the hospital environment. Such activities were invaluable for creating a positive hospital experience for children by combating boredom, enriching choice, and control and reducing a sense of isolation through enhanced socialisation. children want to feel socially connected to the internal hospital community as well as to the outside world. Technology can assist children's social connections when in hospital.
Lambert V. et al (2012)	To describe information exchange between professionals and children in hospital.	Convenience	Qualitative study- Ethnographic processual design.	A variety of information management experiences were encountered by children. Themes - there were issues about the type and amount of information, the flow of the information, comprehension of the information.
Lambert V. et al (2014)	To explore young children's perspectives of ideal physical design features for hospital built environments	Purposive	Qualitative study - interviews incorporating arts based participatory techniques. Data analysed using thematic content analysis.	Three broad themes emerged: personal space; physical environment; and access. Hospital environments need to take account of children's right for privacy, dignity, family support and personal control.

Pelander T. and Leino-Kilpi H. (2004)	To examine children's expectations of quality in pediatric nursing care.	Purposive	Qualitative study. Interviews. Content analysis of data produced codes, categories and subcategories.	Children's expectations related to the nurse; nursing activities and environment. Expectations of nurses:- humane and reliable; good sense of humour and wear colourful clothes. Children expected nurses and parents to undertake nursing activities. Children's expectation of nurses:- entertainment, educational, caring and safety activities. Expected parents to relieve fears and anxieties and keep them company.
Pelander T. et al (2007)	To assess quality of paediatric nursing care as perceived by children.	Purposive	Qualitative study. Interviews and drawings. Content analysis identified themes. Child Care Quality at Hospital Instrument.	Children rated as excellent - environment, nurses' humanity, trustworthiness, caring and communication. Most critical of the nurses entertainment activities - playing with them.
Pelander T. and Leino-Kilpi H. (2010)	To describe children's best and worst experiences of hospitalisation	Convenience	Qualitative study. Questionnaire - Child Care quality at hospital alongside sentence completion exercise.	Children's best experiences related to people, their characteristics, activities, environment and outcomes. Entertainment and objects particularly important to them. Worst experiences related to people, feelings, activities and environment. Being ill; separation; treatment environment and procedures worst aspects for children.
Sartain S.A. et al (2000)	To explore children's , parents' and health professionals' experience of childhood chronic illness.	Purposive	Qualitative study- Grounded theory. Interviews with drawings for prompts. Data analysed using constant comparative analysis.	Children are competent interpreters of their world. Hospitalisation caused disruption to family routines and activities. Children personalised bed space to minimise disruption and alienation and increase familiarity.

Smith L. and Callery P. (2005)	Explore information needs of children experiencing planned surgical admission	Purposive/convenience	Qualitative study. Interviews using draw and write technique. Framework analysis used to analyse data.	Children did not receive direct communication from hospital/professionals. They gathered information via leaflets, television and experiences of relatives and friends. Some children knew little about their admission or surgery. Children identified numerous questions about their hospital admission.
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Design of studies reviewed - health professionals' perspectives

Author (s)	Purpose of study	Recruitment of sample	Methods	Key Findings
Coyne I. and Cowley S. (2007)	Views of children, parents and nurses on participation in care in hospital.	Purposeful sampling	Qualitative study using grounded theory. Interviews and observational data collected. Constant comparative analysis of data.	Parents participation in care was assumed by nurses who saw themselves as facilitators of care. Parent-nurse relationships not real partnerships; parents felt obliged to be present and felt responsible for child's hospital care. Parental contribution to care was relied upon by nurses.
Coyne I. (2006)	Views of children, parents and nurses on participation in care in hospital.	Not fully described	Qualitative study using grounded theory. Interviews, questionnaires and observations. Constant comparative analysis.	Parents and children thought that children should be involved in decision- making processes. Children wanted to be consulted/ informed so that they could be involved in care and prepare themselves for procedures. Professionals' communication behaviours reflected children's cognitive abilities rather than level of understanding. Nurses' views discrepant and involvement of children in decisions about care made without a reliable framework.
Coyne I. (2007)	To investigate parental participation in care from the perspectives of children, parents and nurses.	Purposeful sampling	Qualitative study using grounded theory. Interviews, questionnaires and observation. Constant comparative analysis.	Parents socialised to their role on ward through inclusionary and exclusionary tactics. Nurses controlled parental participation. Expectations of parents were that they would stay with their child, be involved in care and behave properly. Parents not adhering to the norms caused disruption to ward order/ routine. Compliance or non-compliance to norms and rules was rewarded or punished. Nurses depended on parental participation in care - driver for this more organisational efficiency than empowerment.

Coyne I. (2015)	To examine family centred care from child, parent and nurse perspectives.	Purposive	Descriptive qualitative study - interviews with children, parents nurses. Constant comparative analysis.	Nurses positive re: family centred care and rely on families to support care. Families willing to support child's care but greater clarity needed about role and information/support to avoid stress. Delivery of FCC requires resources, management support and nursing skills.
Higham S. and Davies R. , (2012)	To understand fathers' experiences of their child's unplanned hospital stay with acute illness or injury.	Purposive	Ethnographic study. Participant observation and interviews. Data analysed using open coding and interpretation.	Fathers' role: protecting, providing for family and participation in care. Fathers wanted to be with and care for child but faced challenges in balancing responsibilities at work and caring for well siblings. Health professionals need to take account of fathers' role.
Hughes M., (2007)	To explore parents' and nurses' attitudes to family-centred care (FCC).	Random	Quantitative descriptive study. Questionnaires using closed questions, Likert scales. Data analysed using SPSS.	No major differences found between nurses'/ parents' attitudes towards FCC. Parents felt obliged to stay as nurses busy but nurses did not recognise this. Parents unclear about what was expected of them. Parents facilities need improvement..
Paliadelis P. et al (2005)	To explore paediatric nurses' perceptions of how they include and involve parents in the care of hospitalised children.	Purposive	Qualitative study. Interviews. Data analysed by thematic coding.	Four themes identified. Allocation or retention of tasks; nurses' professional identity; barriers and constraints to practising family-centred care; nurses' responsibilities in family-centred care.

Panicker L. (2013)	To explore nurses' perceptions of parent empowerment practices in chronic illness.	Purposive	Qualitative study. Focus group interviews. Thematic content analysis of data.	Empowered parents can take care of their chronically ill child safely at home. Parental empowerment achieved through open communication; sharing decisions; trust; support and parental readiness. Nurses were advocates for child and family.
Peeler A. et al (2015)	To describe parents' and nurses' experiences of infants' hospitalisation for severe bronchiolitis requiring oxygen therapy.	Purposive	Qualitative study. Descriptive phenomenology. Interviews. Colaizzi's approach to data analysis followed.	Mothers extremely fearful that child may die. Lacked knowledge and understanding and ability to fulfil mothering role increased anxieties. Nurses did not fully appreciate the extent of the mothers' fears and tended to focus on procedural aspects of their role. Mothers' emphasis was on physical contact with child and providing comfort. Nurses' focus was on health and safety aspects of care for child and themselves.
Shields L. et al (2004)	To compare parents' and staff's perceptions of parental needs during a child's admission to hospital.	Convenience	Quantitative study. Measures: modified versions of Needs of parents of hospitalized children questionnaire. Data analysed (SPSS). Group and category comparisons.	Some differences between parental and staff perceptions of importance of parental needs and fulfilment of needs but no consistent patterns found. Parents reported themselves more independent than staff perceived them to be.

Simons J. (2002)	To explore parents' support and satisfaction with their child's post-operative care.	Convenience	Mixed methods study Quantitative study. Measures: survey; Nurse Parent Support Tool (NPST); patient charts. Qualitative study. Interviews.	Nurses perceptions of the level of support they were providing to parents was higher than that the level of support parents perceived they received. Parents more satisfied with pain management when child cared for by lower grade nurse and child received more analgesia.
Ygge B.M. (2007)	Examination of nurses' perceptions of parental involvement and communication with parents of children in hospital and differences in perceptions of recently graduated and more experienced nurses.	Purposive	Qualitative study. Focus groups. Constant comparative analysis.	Five themes identified:- clarifying roles; information; work; environment; support and clinical competence. Nurses role as communicator with parents. Nurses need to be aware of the impact of their communication on parents and help clarify the parental role.
Ygge B.M. et al, (2006)	Hospital staff perceptions of parental involvement in children's hospital care.	Convenience	Quant. Cross-sectional study-survey. Factor analysis determining correlations/indices. Statistical analysis using SPSS.	On units where staff reported better work routines for parental involvement less work strain experienced from parental demands. Staff perceptions of parental involvement may relate to specialty.

Judging the quality: parents' perspectives of children's hospital care

Background

The Government set out in 1997 to modernise the National Health Service (NHS) and outlined its future vision and the strategies to achieve this in a range of documents and policies (Department of Health 1997, 2000, 2001a, 2001b, Health and Social Care Act 2001). The re-design of the service incorporated a number of elements aimed at strengthening the position of the patient e.g. greater patient and public involvement, development of a patient advisory liaison service and the launch of the National NHS Patient Experience Survey. These new initiatives were developed in order to address the perceived imbalance of power between patients and health care professionals.

The drive for a patient-centred approach to service provision was further fuelled by some of the disturbing events that occurred in the late 1990s e.g. the Shipman murders, Bristol Children's Hospital Inquiry and the investigation of the retention of organs at Alder Hey Hospital. Public confidence in the NHS was at an all time low with health care professionals coming under increasing scrutiny as their previously unquestioned position of "knowing best" was starting to be challenged.

Patient's choice within the service has been strengthened and in the last month further announcements have been made that patients are now able to choose to be admitted to any Foundation Trust for their care. The combination of patient choice of place of care and the PBR system (payment by results) introduces a true competitive element to service provision. Clearly in a situation where market forces prevail there may be winners and losers in a similar way to that of the commercial world. The more customers i.e. patients/clients, that choose a particular service provider the greater the financial income to that provider. There is then, a financial imperative for health care providers to have a better understanding of the factors influencing the patient's choice if they are to respond and prosper in the future. In the business world the study of the customer's needs and opinions is well recognised as crucial to success. On a more altruistic note, however, it is clear that an appreciation of the patient's perspective of the quality of care provided could offer health care professionals important intelligence of the specific areas of care where improvements are needed to ensure a better experience of care by patients.

In the case of children's health care it will normally be the parents' who will choose their child's place of care. It seems reasonable to anticipate that given a choice parents will inevitably choose a health care provider that they believe

provides high quality care. What is not currently known is how parents make judgements about the level of quality of care provided for their child and which factors influence their overall evaluation and level of satisfaction with the care provided.

In the adult field of health care there is a greater body of knowledge emerging although there are still many gaps in current knowledge. Whilst the literature available includes studies of both patient satisfaction and patient experiences (Carr-Hill 1992, Fitzpatrick 1993, Williams 1994, Edwards and Staniszewska 2000, Aspinall et al 2003, Edwards et al 2003) there has been a recognition that a lack of conceptual and theoretical development with regard to patient satisfaction has limited the extent of progress in this field to date (Staniszewska and Henderson 2005). The effectiveness of patient satisfaction surveys has been questioned as it has become evident that there is often a high level of satisfaction expressed which may not properly reflect the reality of the patient's experiences.

In an effort to examine patient evaluation more thoroughly Edwards et al (2003) explored the ways in which patients construct their expressions of satisfaction using a phenomenological sociological approach. This study highlights some of the complexities of patient evaluation and reinforces the need to continue to develop our understanding of evaluation particularly in relation to how patients form judgements about the quality of care and how this process is influenced by other factors.

It is anticipated that this proposed research study will contribute to a better understanding of these issues within the field of children's health care.

Proposed study

Aim

- To investigate how parents determine the quality of the care provided when their child receives in-patient hospital care
- To determine the factors that will influence parents' perceptions of the quality of care provision for their child
- To identify the potential influences on parents when choosing a future place of care for their child in need of hospital care.
- To develop an explanatory model of the factors determining parents' perceptions of the quality of care provision when their child has received hospital care.

Objectives

- To identify how parents' make judgements of quality of care provided

- To identify the factors influencing the parents' judgements of the components of quality care
- To determine which aspects of care parents' perceive to be of most and least importance to them when judging whether or not the care delivered is of high quality.
- To determine how parents' define and determine high quality of care
- To explore factors which may be most influential in parents' choice of place of care for their child.

In this study the term "care" is used to mean all care that the child received whilst in hospital whether it was clinical, physical, social or emotional. It is also inclusive of care given by all members of staff. This inclusive definition reflects the way in which the child and parents/carers will receive care provision as a whole experience of care rather than separate elements of care by different staff groups.

Methodology

The focus of the research is on the perceptions of parents in relation to the quality of care provision for their child. A qualitative study is proposed to address the research aims and a grounded theory approach will be taken (Strauss and Corbin 1990). The advantage of using this approach in this study is that it will allow the researcher to explore the quality of care provided from the perspective of the parents. Grounded theory requires the researcher to listen fully to the informant's perceptions, experiences and opinions to allow a full appreciation of the participant's perspective of the phenomena under study – in this case the parents' view of quality care provision.

The sample for the study will consist of parents of children (aged 12 and under) who have been admitted for the first time for hospital care in a large NHS Trust. Initially the criteria for potential inclusion to the study sample will be broad and open but as data collection commences and on-going analysis of the data is underway purposive sampling may be used to gain a theoretical sample. It is not possible to be certain at this stage about the detail of the theoretical sample as this will be dependent on the themes which emerge from the initial data. However, it seems reasonable to consider those factors such as – previous experiences of health care, the nature of the illness or injury and parental age/experience may need to be included in a theoretical framework .

Once identified as meeting the inclusion criteria (by the nursing team) parents will be given an information pack containing an invitation to participate in the study. Parents who wish to take part will complete their contact details on an

“expression of interest” form and return this to the researcher. The researcher will then contact the parent/s to set up an interview. Data will be collected through semi-structured interviews with the parents. All interviews will be tape-recorded, transcribed and analysed.

The constant comparative method of data analysis will be used whereby collection, coding and analysis occurs simultaneously (Glaser and Strauss 1967). NVIVO will be utilised to assist in the handling of the data from the interviews. This software package allows data to be given multiple codes according to their source and allows themes to be developed through the process of analysis in an efficient manner. Themes will be identified from the data which will then support the development of an explanatory model of the factors determining parents’ perceptions of the quality of care provision when their child has required hospital care.

This proposed study aims to contribute towards a better understanding of the factors influencing parents’ perceptions of the quality of care provision for their child. It is expected that the findings will assist in illuminating the aspects of care that influence the parents’ perceptions and judgements of the quality of care. It is envisaged that this study will provide useful information for health care professionals and providers in relation to the specific areas of care provision that may require further improvement for parents to judge the care as high quality.

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APPENDIX 12

Parent's Letter



Room D205, Northumbria University
Coach Lane Campus West
Newcastle Upon Tyne

Dear Parent

I am writing to ask you to take part in a research study about children's hospital care. I am interested in quality aspects of children's care and this study aims to find out what parents think are the important aspects of good quality care when their child needs to come in to hospital. I work as a Principal Lecturer at the University of Northumbria at Newcastle (U.N.N.) and I am carrying out this research study as part of my doctoral studies at U.N.N.

If you are willing to take part, I will visit you at a convenient time and place to ask you about your experience and views about when your child was hospitalised. The interview will probably not take more than one hour. I will also invite you to then take part in up to three further interviews .

If you would like to take part, please complete the attached form with your contact details and I will be in touch to arrange to come and talk to you.

Enclosed is an information sheet about the study to help you to decide if you would like to take part.

Ethical approval for this study has been given by [REDACTED] Research Ethics Committee and [REDACTED] NHS Foundation Trust.

Thank you very much for taking the time to read this letter and consider whether or not you wish to be involved in the study.

Yours sincerely

Christine English

Email christine.english@northumbria.ac.uk

APPENDIX 13

Expression of Interest Form



Expression of interest in taking part in this study

Parents perceptions of quality of care

I/We would like to take part in the study and will be happy for you to contact me/us to arrange an interview.

Please complete your contact details below.

Name

Address

Telephone Number

Email



Judging the quality: parent's perspectives

Research Information Sheet

I am interested in quality aspects of children's care and this study aims to find out what parents think are the important aspects of good quality care when their child needs to come in to hospital. I currently work as a Principal Lecturer at the University of Northumbria at Newcastle (U.N.N.). I am carrying out this research study as part of my doctoral studies at U.N.N.

This sheet contains information to help you decide whether or not to take part in this study. If you would like more information, my contact details are given at the end – please do feel free to ask me about any aspect of the study.

How will this study help?

The findings from this study will help professionals to have a better understanding of what aspects of care really matter to parents when their child is hospitalised. *In this study the term "care" is used to mean all care that the child received whilst in hospital whether it was clinical, physical, social or emotional. It includes care given by all members of staff.*

Why am I being invited to participate?

I am asking parents of children (under 12 years old) who have experienced their child being admitted to hospital, to take part in the study. You do not have to take part, and if you do take part you can withdraw at any time without this affecting your child's care.

What am I being asked to do?

If you do agree to take part, I will arrange to visit you to ask you about your experience. I can visit you at home or at another convenient venue. With your permission, the conversation will be tape recorded, to make sure that your comments are recorded accurately. The conversation will probably last about 45-60 minutes. You will also be invited to take part in up to three further follow up interviews.

What are the benefits of taking part in the study?

By asking parents about their experiences and opinions about the aspects of their child's care that were important and most valued by them I hope that this information will be helpful for professionals in improving the quality of care for children and their parents.

What are the risks in being involved?

Whilst risks for parents taking part are minimal, I am aware that talking about your child being ill or injured may be upsetting. If you were to become upset during the conversation, the interview can be stopped at any point.

Only myself and my two supervisors will know who has taken part and what comments they have made. I will not tell staff who looked after your child that you have taken part in the study. If you do agree to take part, you can withdraw or stop the conversation at any time. The comments made by parents involved in the study will be anonymous, so those reading the report of the research will not be able to know who said what.

If you express concerns about care during the interviews I will discuss with you the options available to you to deal with those concerns informally or formally.

Will I be told the results?

Once the research is complete a summary of the results will be sent to parents who have taken part.

Who can I talk to if I have more questions?

Please feel free to discuss your involvement with others or contact me (see details below) if you would like to know more.

My contact details;- Christine English
Room D205
Northumbria University
Coach Lane Campus (West)
Newcastle Upon Tyne
NE7 7XA telephone – 0191 215 6321
or **email: christine.english@northumbria.ac.uk**

If you are unhappy with any aspect of this research study or about the researcher, please contact: Professor Charlotte Clarke

**Associate Dean (Research)
Northumbria University
Coach Lane Campus West
Newcastle Upon Tyne, NE7 7XA
0191 215 6075
charlotte.clarke@northumbria.ac.uk**



Judging the quality: the parents' perspective

Consent Form

Please initial each box

I have read and understand the purpose of the study

I have had my questions about the study answered to my satisfaction

I am willing to be interviewed

I am happy for my comments to be tape recorded

I understand that I can withdraw at any time and this will not affect my child's care or my care in anyway

I know that my details will be kept confidential and will not appear in any printed documents

I am willing for information I provide to be used within a doctoral thesis by Christine English

.....

Name of participant	Date	Signature
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.....

Researcher	Date	Signature
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1 copy for researcher/ 1 copy for participant/1 copy for patient's notes

Overview of Participants

In accordance with the requirements to protect anonymity and confidentiality the participants have been given pseudonyms (Nursing Midwifery Council, 2015) and will be referred to by these names throughout the thesis. Efforts have been made to remove any features to the accounts that may enable identification of individuals involved or the participant's children.

Brian

Brian is the father of a little boy, Nathan, who sustained a fractured skull after falling from his pram onto the ground when he was six months old. He was taken by car to hospital by his mother and father, they were then sent to another hospital where Nathan was x-rayed. He then had a brain scan and was admitted to hospital for neurological observations. The following day he was able to go home.

Angela and Graham

Angela and Graham have two children - Louise and Jonathan. They have had a number of hospital experiences with both children.

Louise has been an in-patient on two occasions. Her first admission was as an emergency with a life threatening infection when she was 7 years old. She was seriously ill and in hospital for two weeks but made a full recovery from the illness. Her second admission was as an emergency with abdominal pain and after a number of days of investigation and observation an appendectomy was

performed. She has also been seen in the accident and emergency unit with acute breathlessness following a PE class at school and on another occasion she was seen with a painful hip.

Jonathan has been a patient in the accident and emergency unit where he was assessed following an episode of abdominal pain and vomiting when he was ten years old. He also was assessed in the orthopaedic unit with an irritable hip of unknown cause. On another occasion when he was eight years old he had accidentally taken one travel sickness tablet too many and had to be admitted and observed on a day assessment unit.

Angela is a children's nurse and is familiar with the hospital in her professional role but also as a parent.

Gina and Derek

Gina and Derek have two children - Thomas and Lucinda. Thomas was born with a number of congenital abnormalities and has learning difficulties. They have had numerous hospital experiences with Thomas as an in-patient, day patient and out-patient across a range of specialised services.

He is now 5 years old and attends a school for children with special needs and has on-going support from a range of professionals through the education system. Thomas continues to be monitored on a regular basis in the children's out-patient services. The Clinical Genetics Service continues to link with other centres worldwide in efforts to uncover any possible genetic explanation for Thomas's physical and mental problems.

Both Gina and Derek had little experience with hospital services prior to Thomas's birth.

Wendy

Wendy is married and has two children Dawn and Billy. Dawn was 8 years old when Wendy noticed that Dawn had a thrush infection and she had also been losing weight despite eating normally. She had lost approximately a stone in weight in one month and was tired. Wendy took Dawn to the GPs due to the thrush infection but mentioned the weight loss whilst she was there. The GP took some blood from Dawn but reassured Wendy that the tests would probably come back normal but she thought they should check.

When Wendy got home that evening she received a phone call from the GP to say that Dawn's blood test showed that her blood sugar was high and that she had diabetes. Wendy had to take Dawn to the hospital for further tests where they were able to confirm this diagnosis and begin teaching Dawn and her parents how to manage her care at home.

Wendy had limited experience of hospital prior to Dawn's admission. Her previous experiences of being a patient were when she had given birth to her children and when she had knee surgery as an in-patient as an adult. Wendy had not experienced hospital herself as a child or as a parent of a child until Dawn was admitted with diabetes.

Norma

Norma is married and has two children Lana and Amy. Lana is now 6 years old and has a chronic condition and needs to attend the hospital on a weekly basis for intravenous infusions of drugs. She potentially may require a bone marrow transplant in the near future to treat the disease but a second opinion is awaited

from another specialist before this will be confirmed. Norma has had experiences of her daughter attending hospital as an in-patient and a day patient since she was a baby. Some admissions have been planned and others have been urgent. During the time that they have been attending the hospital there have been major changes to the hospital, ward locations and staff.

Mary

Mary is the grandmother of Jennifer a five year old girl with asthma. Jennifer lived with her grandmother and mother but grandmother regular cared for Jennifer when her mother was at work each night. One evening when her grandma was looking after her Jennifer was unwell and had some breathing problems so her grandma took her to the assessment unit at the hospital. Jennifer had been to her GP and to the hospital with her asthma in the past as a toddler. Mary worked as a carer with adults with learning difficulties and had some experience of accompanying these adults to hospital and doctors appointments.

Helen

Helen is married to Russell and has two children James and Justin. When Justin was a baby he was admitted to the intensive care unit with a life threatening infection. He was extremely ill and initially the prognosis was very poor. He did recover but needed to have his leg amputated due to the tissue damage from the infection. He was cared for in the intensive care unit for many weeks before being transferred to a children's ward and later discharged home. He has had a number of operations over the years (he is now twelve years of age) and has had regular hospital contacts through the rehabilitation and prosthesis services as well as the orthopaedic out- patient service.

Coding summary

Focused coding	Theoretical coding	'on guard and on behalf' with or without allies
Two worlds	Landing in an alien hospital world	
Alien hospital world		
Family's outside world		
Sudden shock		
Landing		
Biographical disruption		
Heightened emotions		
Anticipation of short or long term in this world		
Searching for clues	Moving from being new parents to old hands	
Giving information without meaning		
Thinking ahead a step		
"we now know"		
Insider knowledge		
New parents - personal life perspectives and lens		
Making sense of the clues and altering the lens		
Being alone or having allies		
Judging the clues	Judging and responding	
To say or not to say		
Thinking something		
Asking/mentioning something		
Saying or doing something		
Judging the quality		
'at the time' view		
'on balance' view		

Conference presentations from this study

12th International Family Nursing Association (IFNA) Conference, August 18-21, 2015, Odense, Denmark

Concurrent session entitled:

Judging Quality: Parents' perspectives of the quality of their child's hospital care.

3rd Paediatric Nursing Associations of Europe (PNAE) Congress, June 7-8, 2013, Glasgow, Scotland.

Poster presentation entitled:

Parents' perspectives of the quality of their child's hospital care.

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